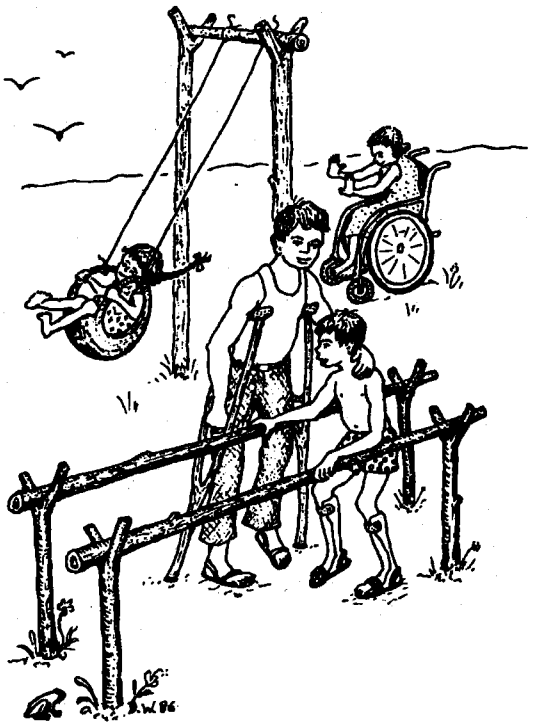
Disabled Village Children

A guide for community health workers, rehabilitation workers, and families

By David Werner
with the help of many friends



Adapted for India by
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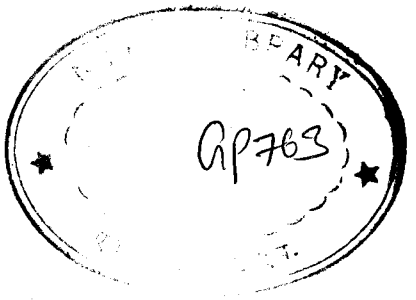
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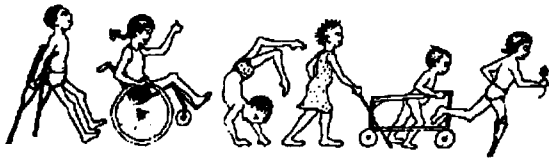
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David Werner

Preface

Disabled Village Children

This is a book that is useful for everyone- community workers, parents of disabled children- professionals. To the community worker it shows a multitude of ways to use the resources available in the community for the rehabilitation of the disabled child.

The book empowers parents and families by giving them information about disabilities as well as what to do, to help the child without incurring large expenditure. It also encourages them to innovate on their own.

To the professionals, it's an eye opener on how much of rehabilitation is possible at a very low cost. It also points out that more often than not it is the parents, families that come up with excellent ideas and ways to help the child.

This book is also very much about the dignity of the disabled person, not just as a receiver but as a person in his own right.

Emphasis is also given to the prevention of the major disabilities and this would be of great help to the community worker.

The book also has deals with issues such as work, education, adapting the community for the needs of disabled children, and the rights of a person with a disability to a full life.

As the author points out, it is not a book written in a top-down fashion, but a book that has really originated from the collective wisdom of many community based projects. We will consider the effort meaningful unless this user friendly reaches every organization and individual trying to meet the gigantic task of meeting the unmade needs of the millions of disabled in India and other South countries.

Alok Mukhopadhyay

This book is dedicated to disabled children everywhere,
with the hope that they and their families
will help lead the world
to be more loving, understanding,
and just for everyone.

REQUEST FOR YOUR SUGGESTIONS, CRITICISMS, AND IDEAS

This book is an attempt to pull together basic information to help you meet the needs of village children with a wide range of disabilities.

We have done the best we can, given our limitations. We know the book is not perfect and that it has weaknesses and perhaps some mistakes.

We urge anyone reviewing or using the book, whether a disabled person, parent, health worker, or professional, to send us all your criticism and suggestions. Help us to make improvements, for a later edition. Thank you.



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ABOUT THIS BOOK

A TRUE STORY : CRUTCHES FOR PEPE

A teacher of village health workers was helping as a volunteer in the mountains of western Mexico. One day he arrived on muleback at a small village. A father came up to him and asked if he could cure his son. The health worker went with the father to his hut.

The boy, whose name was Pepe, was sitting on the floor. His legs had been paralyzed by polio, from when he was a baby. Now he was 13 years old. Pepe smiled and reached up a friendly hand.

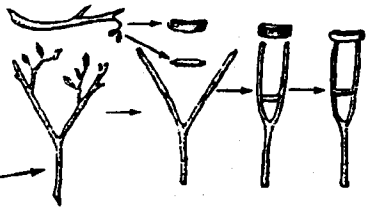
The health worker, who also had a physical disability, examined Pepe. "Have you ever tried to walk with crutches?" he asked. Pepe shook his head.

"We live so far away from the city," his father explained.

Let's try to make some crutches," said the health worker.

The next morning the health worker got up at dawn. He borrowed a long curved knife and went into the forest. He looked and looked until he found 2 forked branches the right size.

He took the branches back to Pepe's home and began to make them into crutches, like this.



The father came and seeing the crutches, he said, "they won't work!"

The health worker frowned. "wait and see!" he said.

When both crutches were finished, they showed them to Pepe, who was eager to try them. His father lifted Pepe to a standing position and the health worker placed the crutches under the boy's arms.

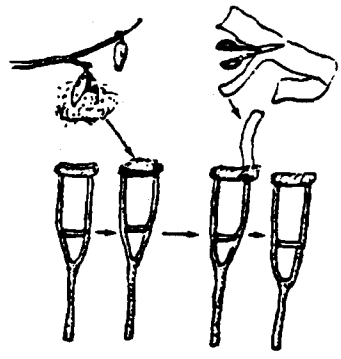
But as soon as Pepe put his weight on the crutches, they bent and broke.

"I tried to tell you they wouldn't work," said the father. "It's the wrong kind of tree. Wood's weak as water! But now I see your idea. I'll go cut some branches of 'j'utamo'. Wood's tough as iron, but light! Don't want the crutches too heavy."



He took the knife and went into the forest. Fifteen minutes later he was back with 2 forked branches of 'j'utamo'. He began making the crutches, his strong hands working rapidly. The health worker and Pepe helped him.

When these crutches were finished, Pepe's father tested them by putting his own weight on them. They supported him easily, yet were lightweight. Then Pepe tried them. At first, he had trouble balancing, but soon he could hold himself up. By afternoon, he was walking with the crutches! But they rubbed under his arms.



"I have an idea," said Pepe's father. He ran to a wild kapok tree, and picked several of the large ripe fruits. He gathered the soft cotton from the pods and put a cushion of kapok on the top crosspiece of each crutch. He wrapped kapok in place with strips of cloth. Pepe tried the crutches again. They were comfortable.

"Thanks, Papa, you fixed them great!" he said, smiling at his father with pride. "Look how well I can walk now!" He moved about quickly in front of them.

"I'm proud of you, son!" said his father, smiling too.

As the health worker prepared to leave, the whole family came to say goodbye.

"I can't thank you enough," said Pepe's father. "It's so wonderful to see my son walking. I don't know why I never thought to making crutches before.."

"I should be thanking you", said the health worker. "you have taught me a lot."



After leaving, the health worker smiled to himself. He thought, "How foolish of me not to have asked the father's advice in the beginning. He knows the trees better than I do. And he is a better craftsperson.

"But it was good that the crutches I made broke. Making them was my idea, and the father felt bad for not thinking of it himself. But when my crutches broke, he made much better ones. That made us equal again!"

So the health worker learned many things from Pepe's father - things that he had never learned in school. He learned what kind of wood is best for making crutches. He also learned how important it is to use the skills and knowledge of the local people - because a better job can be done, and because it helps maintain people's dignity. People feel equal when they learn from each other.

HOW THIS BOOK WAS WRITTEN

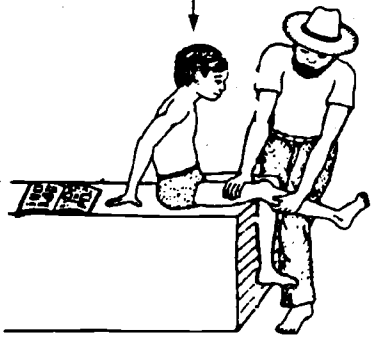
The story of Pepe's crutches is an example of the lessons we have learned that helped to create this book. We are a group of village health and rehabilitation workers who have worked with people in farming communities of western Mexico to form a 'villager-run' rehabilitation program. Most of us on the rehabilitation 'team' are disabled ourselves.

From our experience of trying to help disabled children and their families to meet their needs, we have developed many of the methods, aids, and ideas in this book. We have also gathered ideas from books, persons, and other programs, and have adapted them to fit the limitations and possibilities of our village area. We hope this book will be useful to village people in many part of the world. So we have asked for cooperation and included suggestions from community program leaders in more than 20 countries.

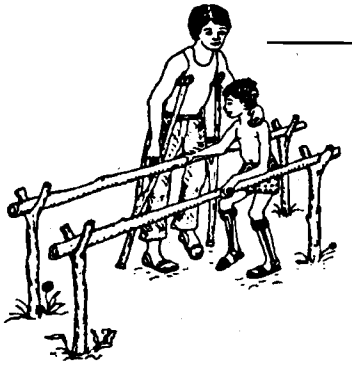
This book was *not* written by experts,



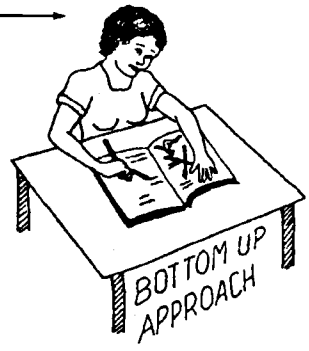
and then 'field tested' with community workers



instead, it was written by and with community workers,



and then reviewed and corrected by experts.



Unlike most handbooks for village workers and families, this book was not written by 'professionals' and then 'field tested'. Instead, it grew out of the practical experience of a team of disabled village health workers as we looked for information to help meet the most common problems we face.

However, a large number of professionals have helped in important ways. Many are well-known leaders in their fields. They include physical and occupational therapists, special educators, nurses, doctors, brace and limb makers, and rehabilitation engineers. They have carefully reviewed and even helped to rewrite sections of this book. Some have also helped to teach and advise our village team.

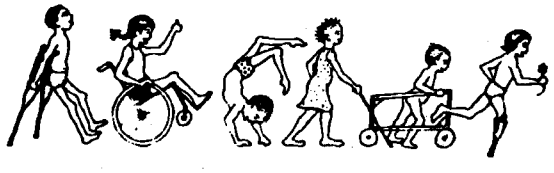
HOW THIS BOOK DIFFERS FROM OTHER 'REHABILITATION MANUALS'

This book was written from the 'bottom up', working closely with disabled persons and their families. We believe that those with the most personal experience of disability can and should become leaders in resolving the needs of the disabled. In fact, the main author of this book (David Werner) and many of its contributors happen to be disabled. We are neither proud nor ashamed of this. But we do realize that in some ways our disabilities contribute to our abilities and strengths.

In many rehabilitation manuals, disabled persons are treated as objects to be worked upon, to be 'normalized' or made as normal as possible. As disabled persons, we object to attempts by the experts to fit us into the mold of normal. Too often 'normal' behavior in our society is selfish, greedy, narrow-minded, prejudiced- and cruel to those who are weaker or different from others. We live in a world where too often it is 'normal' and acceptable for the rich to live at the expense of the poor, and for health professionals to earn many times the wages of those who produce their food but cannot afford their services. We live on a wealthy planet where most children do not get enough to eat, where half the people have never seen a trained health worker, and where poverty is a major cause of disability and early death. And yet the world's leaders spend 50 billion dollars every 3 weeks on the instruments of war- an amount that could provide primary health care to everyone on earth for an entire year!

Instead of being 'normalized' into such an unkind, unfair, and unreasonable social structure, we disabled persons would do better to join together with all who are treated unfairly, in order to work for a new social order that is kinder, more just, and more sane.

This large book, then, is a small tool in the struggle not only for the liberation of the disabled, but for their solidarity in the larger effort to create a world where more value is placed on being human than on being 'normal' - a world where war and poverty and despair no longer disable the children of today, who are the leaders of tomorrow.



Top-down rehabilitation manuals too often only give orders telling the 'local trainer', family member, and disabled person exactly what they 'must do'. We feel that this is a limiting rather than liberating approach. It encourages people to obediently fit the child into a standard 'rehabilitation plan', instead of creating a plan that fits and frees the child. Again and again we see exercises, lessons, braces, and aids incorrectly, painfully,, and often harmfully applied. This is done both by community rehabilitation workers and by professionals, because they have been taught to follow standard instructions or prepackaged solutions rather than to respond in a flexible and creative way to the needs of the whole child.

In this book we try ***not*** to tell anyone what they ***must*** do. Instead we provide information, explanations, suggestions, examples, and ideas. We encourage an imaginative, adventurous, thoughtful, and even playful approach. After all, each disabled child is different and will be helped most by approaches and activities that are lovingly adapted to her specific abilities and needs.

As much as we can, we try to **explain basic principles** and **give reasons for doing things**. After village rehabilitation workers and parents understand the basic principles behind different rehabilitation activities, exercises, or aids, they can begin to make adaptations. They can make better use of local resources and of the unique opportunities that exist in their own rural area. In this way many rehabilitation aids, exercises, and activities can be made or done in ways that **integrate rather than separate** the child from the day-to-day life in the community.

This is not the first handbook of 'simplified rehabilitation'. We have drawn on ideas from many other sources. We would like to give special credit to the World Health Organization's manual, ***Training the Disabled In the Community,*** and to UNICEF and Rehabilitation International's ***Childhood Disability : Prevention and Rehabilitation at the Community Level,*** a shortened and improved version of the WHO manual. The WHO manual has recently been rewritten in a friendlier style that invites users to take more of a problem-solving approach instead of simply following instructions.

This handbook is not intended to replace these earlier manuals. It provides additional information. It is for those families, village health workers, and community rehabilitation workers who want to do a more complete job of meeting the needs of physically disabled children.

HOW WE DECIDED WHICH DISABILITIES TO INCLUDE

Because this book is written for village use in many countries, it was not easy to decide what to include. People in different parts of the world give importance to different disabilities. This is partly because some disabilities are much more common in one area than another. For example,

- **polio** in some countries is the most common disability. In others, it is rare because of effective vaccination programs.
- **deafness** and **mental retardation** are much more common in certain mountain regions because of lack of iodine in the diet (or in salt).
- **blindness** due to lack of vitamin A is common in some poor crowded communities, and depends a lot on local food habits.
- **rickets** is still common in regions where children are wrapped up or kept in dark places so much that they do not get enough sunlight.
- **lathyrism** is a major problem among the landless labourers, who get *khesari dal* as wages and become victims of severe paralysis of the lower limbs.
- **burn deformities** are frequent where people cook and sleep on the ground near open fires.
- **amputations** are a big problem in war zones, refugee camps, and 'shanty towns' along railway tracks.
- disability from **tuberculosis, leprosy, measles, malnutrition, and poor sanitation** are especially common where lack of social justice lets some people live in great wealth while most live in extreme poverty.

Local beliefs also effect how people see different disabilities. In an area where people **believe** that **fits** are the work of the devil, a child with fits may be feared, teased, or kept **hidden**. But in places where everyone accepts fits as 'just something that happens to **certain** persons' a child who sometimes has fits may participate fully in the day-to-day life **of the** community, without being seen as 'handicapped'. Both of these children need **medicine**. But probably only the mistreated one needs 'rehabilitation'.



It is important to consider how local people see a child who is in some way 'different'. How do they accept or treat the child who learns slowly, limps a little, or occasionally has fits?

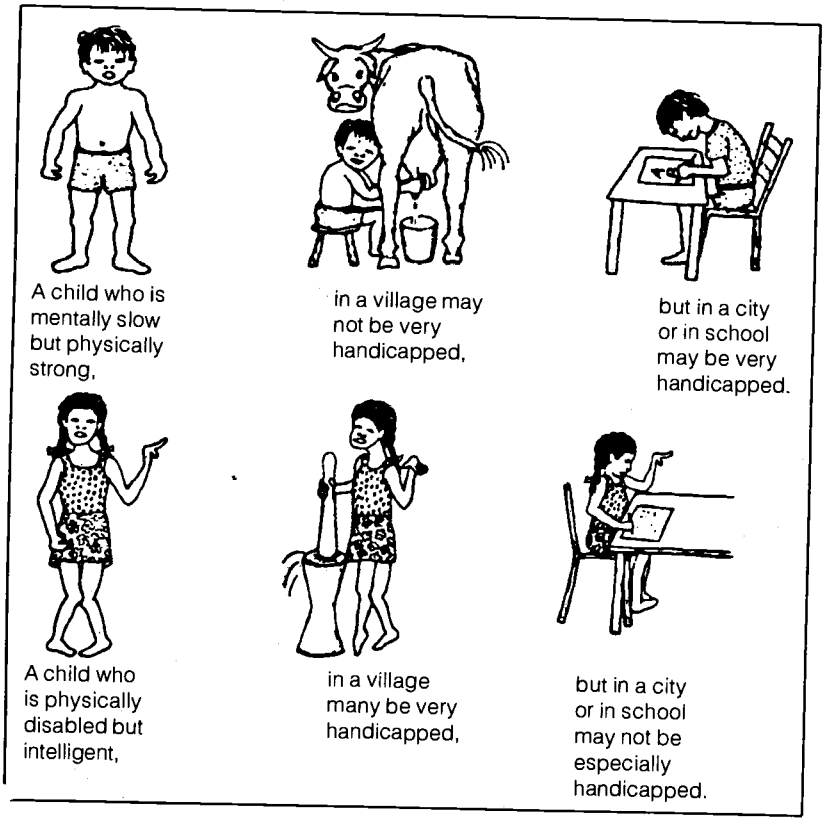
Many reports say that in both rich and poor countries, 1 in 10 children are disabled. However, this number can be misleading. Although 1 child in 10 may show some defect if examined carefully, most of these defects are so minor that they do not affect the child's ability to lead a full, active life. In rural areas, children who are physically strong but are slow learners often fit into the life and work of the village without special notice. In India, a study found that only 1 in 7 of those recorded as mentally retarded by screening tests were seen as retarded by the community.

Studies in several countries show that, on the average, only 2 or 3 children in 100 are considered disabled by the community. These are the children most likely to benefit from 'rehabilitation'.

> *CAUTION:* If the community does not consider a child 'disabled', and the child manages well, it may be wiser not to bring attention to her condition. To do so might actually 'disable' the child more in the eyes of the community, and make life harder for her. Think carefully before deciding to do a 'complete survey' on disability.

When we started to write this book, we planned to include only physical disabilities. This is because **concerned villagers and health workers in rural Mexico considered physical handicaps to be the area of greatest need.**

This is understandable. In poor farming communities, where many day-to-day activities depend on physical strength, and where schooling for most children is brief, the physically disabled child can have an especially difficult time fitting in. By contrast, in a middle-class city neighborhood, where children are judged mainly by their ability in school, it is the mentally slow child who often has the hardest time.





The team of disabled village workers in Mexico was at first concerned mostly with physical disabilities. But they also had to learn about other disabilities. Even children whose main problem was physical, like polio, were often held back by other (secondary) emotional, social or behavioral disabilities. And many children with brain damage not only had difficulties with movement, but also were slow learners, had fits, or could not see or hear.

As the PROJIMO team's need for information on different disabilities has grown, so has this book. **The main focus is still on physical disabilities,** which are covered in more detail. However, the book now includes a fairly complete (but less detailed) coverage of **mental retardation and developmental delay** (slow learning). **Fits** (epilepsy) are also covered.

Blindness and deafness are included. Some fairly good instructional material is available on these disabilities, especially on blindness. We list some of the best materials that we know on p.771 and 772.

Note: This book does not include disabilities which are mainly in the area of internal medicine, such as asthma, chronic lung problems, severe allergies, heart defects, diabetes, bleeding problems, or cancers. In local areas where such disabilities are common, rehabilitation workers should obtain information separately.

To decide which disabilities to put in this book and how much importance to give to each, we used information from several sources, including the records of Project PROJIMO in Medico. We found that the numbers of children with different disabilities who came to PROJIMO were fairly similar to those in studies done by WHO, UNICEF, and others in different areas of the world.

On the next page is a chart showing how many children with each disability might be seen in a typical village area. (Of course, there is no such thing as a 'typical' village. The patterns of disability in some areas will be quite different from those shown on the chart.) The chart is based mainly on our records from PROJIMO over a 3-year period.

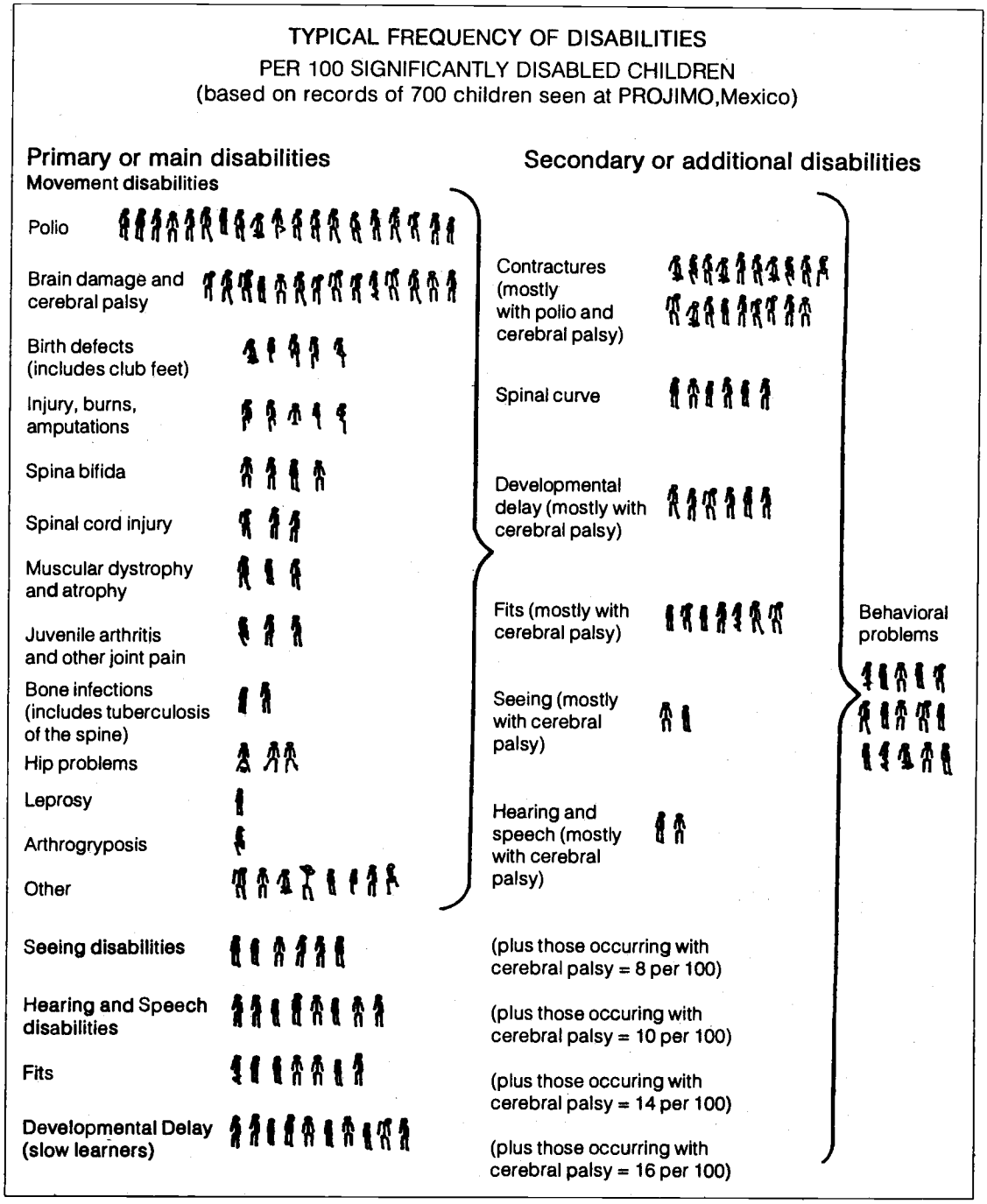
Notice that in the chart, the number of children with each disability corresponds more or less to the relative importance that we give to each disability in this book. In certain cases we have made exceptions. For example, few persons with leprosy have come to PROJIMO. But we have included a long chapter on leprosy because we realize it is a big problem in some places.

IMPORTANT: The disabilities discussed in this book are those that are most common in rural areas in many countries. But not all disabilities are included. Also, certain disabilities may be difficult to identify, or require special tests or analyses. **When in doubt, try to get advise from persons with more training and experience.**

Clearly you cannot solve every problem. But **there is much you can do.** By asking questions, carefully examining the child, and using whatever information and resources you can find, you may be able to learn much about what these children need and to figure out ways to help them manage better.

HOW COMMON ARE DIFFERENT DISABILITIES

The little 'stick people' in this chart show how many children might have each disability in an average groups of 100 significantly disabled village children. These figures are based on records of 700 children seen at PROJIMO, Mexico (1982-1985), and other studies. The numbers in your area may be similar or very different from these, depending on local factors.



Note: Seeing and hearing disabilities, fits, and developmental delay are listed in 2 places, depending on whether they are the main disability or occur in addition to some other disability.

Note to

REHABILITATION PROFESSIONALS, PROGRAM PLANNERS, AND THERAPISTS

You may think that this book is 'too complex' or 'too long' for community health workers or rehabilitation workers, or family members. At first, for many, it may be. This is a book to grow into-a simplified but detailed work book and reference book.

But remember,**almost all the ideas and information in this book are right now being put into practices by village workers with little schooling, together with disabled children and their families.** The book was developed for and with a team of village workers who have an average of 3 years primary school education.

Some health workers and parents will be able to make fairly good use of the book, or parts of it, without special training. Other will not.

This book is not intended to be a substitute for 'learning through guided practice'. People learn best when someone with more experience shows and explains things to them in a real situation (working with disabled children and their families). Skills for making aids and teaching exercise are also learned best by working with an experienced rehabilitation worker or craftsperson.

In some places, or when a village program is just beginning, this book may at first be used mainly by program leaders, therapists, and instructors to help you learn to teach in ways that communicate clearly and that encourage a problem-solving approach. The book can also be a resource to help you answer questions that village workers will have after they start working with disabled children.

We have observed that when making decisions about what a child needs, some rehabilitation professionals, therapists, aid makers, and surgeons do not think enough about the whole child, the situation where she lives, the money problems, or the resources within the family and community. As a result, much too often the professionals make decisions that are not practical or that sometimes do more harm than good (see Chapter 57). Often their recommendations fail because they have tried to fit the child into their textbook, instead of adapting the textbook to fit the child and her situation. This comes partly from many years of conventional schooling, which encourages 'following instructions' more than 'thinking things through' and 'being creative'

There will never be enough highly-trained rehabilitation professionals to attend to the needs of more than a small part of the world's millions of disabled persons. Most rehabilitation and therapy can and should take place in the home and community with loving support of family, neighbors, and friends.

You rehabilitation professionals and therapists can play an extremely important role in 'community-directed rehabilitation'. By simplifying and sharing your knowledge and skills, you can reach many more children. But to do this you will need to go out of the large city rehabilitation centers and into neighborhoods and villages. You will need to meet and work with the people on their terms, as learners, teachers, and information providers. You can help disabled persons, parents, and other concerned individuals to organize small, community-directed centers or programs. You can teach those who have the most interest to become teachers. You can help local craftspersons to figure out or improve low-cost designs for rehabilitation aids (and they can help you). You can encourage village leaders to improve paths and entrances to schools and public places. You can help local people to understand basic principles and to avoid common mistakes, so that they can be more effective leaders and participants in home and community rehabilitation.

IMPORTANT: RESPECT THE KNOWLEDGE AND SKILLS OF THE PEOPLE

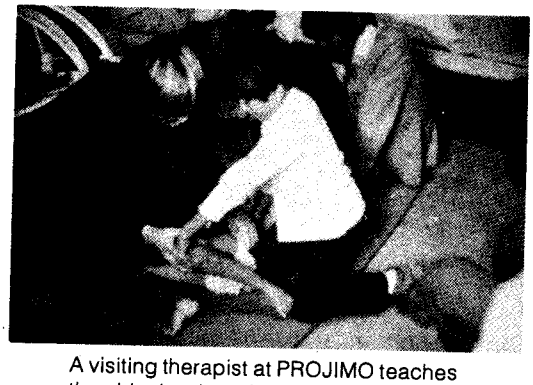
Villagers are often much better than city persons at figuring out how to do things, at using whatever happens to be available, and at making and fixing things with their hands. In short, they are more 'resourceful'. They have to be to survive! **This 'resourcefulness' of village people can be one of the most valuable 'resources' for rehabilitation in rural areas.**

But for this to happen, **we need to help people understand basic principles and 'concepts' - not just tell them what to do.** Above all, we need to respect their intelligence, their knowledge of the local situation, and **their ability to improve on our suggestions.**

Whenever possible, arrange for village workers to learn to use this book with guidance from experienced rehabilitation workers. Those rehabilitation workers should be able to listen to the people, respect their ideas, and relate to them as equals.

For best learning, the teacher, or 'guide' should stay as much in the background as possible, offering friendly advice when asked, and always asking the learners what they think before giving instructions and answers.

It is our hope that this book may help disabled persons, their families, village workers, and rehabilitation professionals to **learn more from each other,** and to help each other to become more capable, more caring, human beings.



A visiting therapist at PROJIMO teaches the older brother of a disabled girl how to do stretching exercises of her hip to correct a contracture.



NOTE ON LANGUAGE USED IN THIS BOOK



Speaking of the Disabled Child – 'SHE' or 'HE'

Many studies have shown that more boys are disabled than girls. it is sometimes argued that this is because boys are more exposed to physical stress and danger, or because of sex-linked 'genetic' factors.

But there may also be other, more disturbing reasons why reports show so many more disabled boys than girls.

- Of those who are disabled, more of the boys than the girls are taken to medical centers where their disabilities are recorded.

- Disabled girls often are not cared for as well as disabled boys; therefore more of the girls die when they are babies or small children.

In short, **disabled boys often receive better attention than do disabled girls.** This, of course, is not surprising: in most countries, non-disabled boys also get better treatment, more food, and more opportunities than do non-disabled girls.

Most literature on disabled children speaks of the disabled child as 'he'. This is partly because male dominance is build into our language. However, we feel this can only add to the continued neglect of the so-called 'weaker sex'.

In this book, therefore, we have made an effort to be fair, but rather than to always speak of the child as 'he-or-she' or 'they', which is awkward, we sometimes refer to her as 'she' and sometimes as 'he'.

If at times this is confusing, please pardon us. And if we sometimes slip and give more prominence to 'he' than 'she', either in words or pictures, please criticize but forgive us. We too are products of our language and culture. But we are trying to change.



Speaking of the Author(s): 'WE' or 'I'

Although one person has done most of the writing of this book, many persons have shared in its making (see the 'Thanks' page at the beginning of this book.) Therefore, when speaking from our authors-advisers' viewpoint, we usually use 'we'. This book is a group effort.

PART 1

WORKING WITH THE CHILD AND FAMILY

Information on Different Disabilities

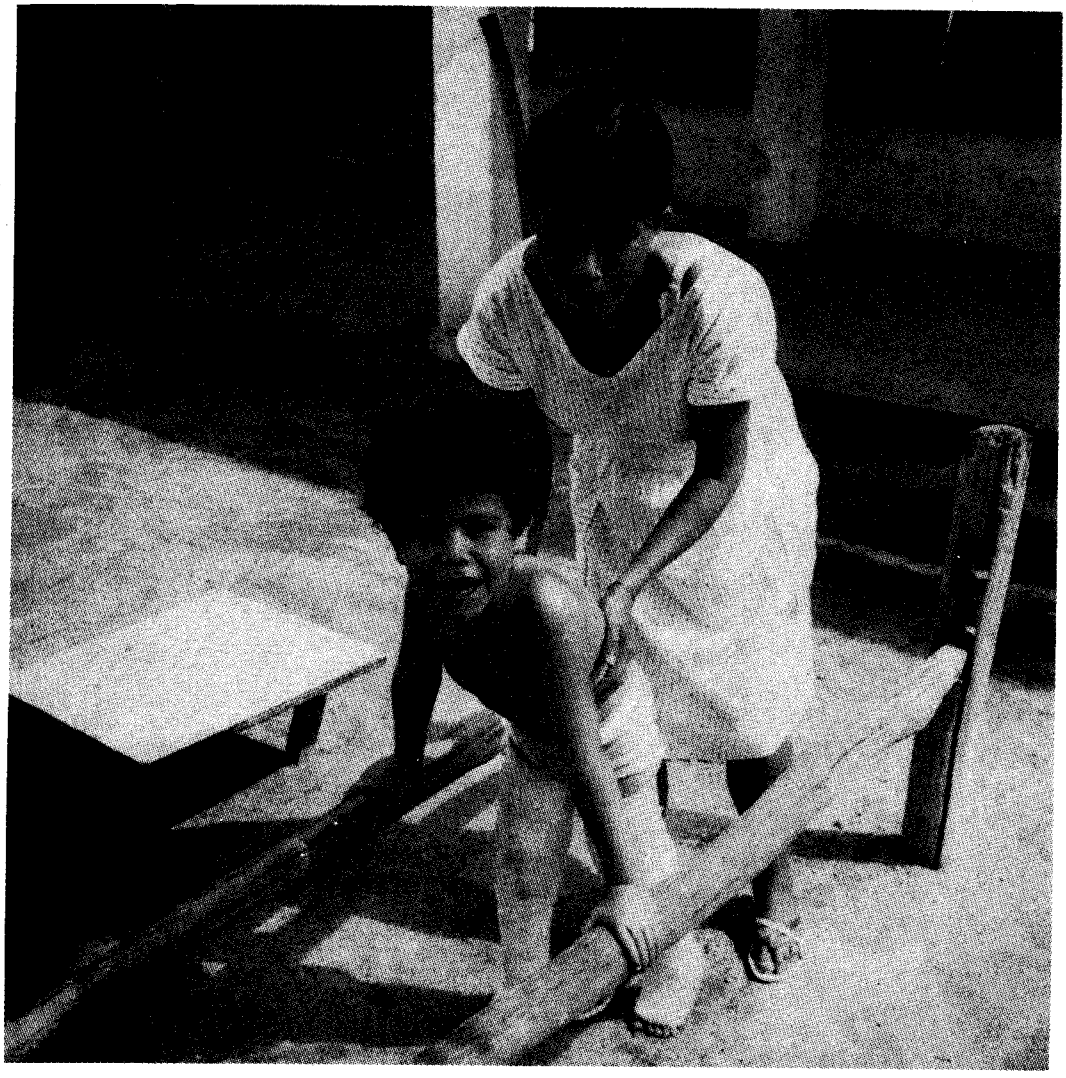


Photo by John Fago



Photo by John Fago

INTRODUCTION TO PART 1

CHAPTER **1**

Making Therapy Functional and Fun

Most disabled people in the world live in villages and poor communities where they never see a 'rehabilitation expert' or 'physical therapist'. But this does not always mean that they have no 'rehabilitation' or 'therapy'. In many villages and homes, family members, local craftspersons, traditional healers, and disabled people themselves have figured out ways for persons with disabilities to do things better and move about more easily.

We have seen examples where local carpenters, tinsmiths, leatherworkers or blacksmiths have put together simple crutches, carts, wooden legs and other aids. We know parents who have figured out ways of adapting daily activities so that their children can help do farm work or housework-and at the same time get much of the exercise (therapy) they need.

Sometimes the 'rehabilitation' that families and communities figure out by themselves works better in their situation than do methods or aids introduced by outside professionals. Here are 2 examples:

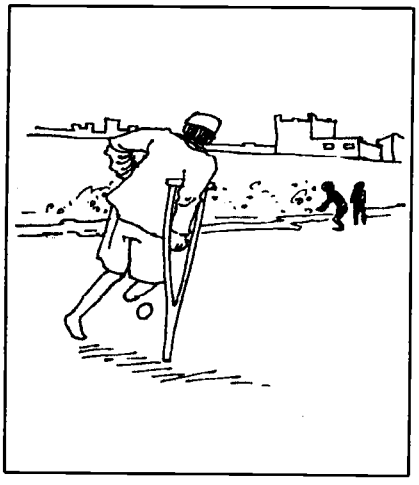
1. In India, I (David Werner) met a villager who had lost a leg in a house-building accident. Using his imagination, he had made himself an artificial leg with a flexible foot out of strong wire with strips of an old cotton blanket for padding. After several months, he had the chance to go to a city where a professional 'leg maker' (prosthetist) made him a costly modern fiberglass leg. The man tried using the new limb for a couple of months, but it was heavy and hot. It did not let his stump breathe like his 'wire cage' leg. And he could not squat to eat or do his toilet, as he could with his homemade leg. Finally, he stopped using the costly new leg and went back to the one he had made. For the climate and customs where he lived, it was more appropriate.

Two words often used by people who work with disabled persons are ***'rehabilitation'*** and ***'therapy***.

Rehabilitation means **returning of ability**, or helping a disabled person to manage better at home and in the community.

Therapy basically means treatment ***Physical therapy*** – or physiotherapy – is the art of improving position, movement, strength, balance, and control of the body. ***Occupational therapy*** is the art of helping a disabled person learn to do useful or enjoyable activities.

We speak of 'therapy' as an **art** rather than a science because there are many different beliefs and approaches, and because the human feeling that goes into therapy is as important as the methods.



All children, as much as possible, should get the exercise they need through daily work and play.

2. In a small village in Mexico, over the years, the community together with its deaf citizens has developed a simple but expressive 'sign language' using their hands, faces, mouths, and whole bodies to communicate. As a result, children who are born deaf quickly and gracefully learn to express themselves. They are well accepted in the community, and some have grown up to become creative and respected craftspersons. This village method of 'total communication' allows the deaf children to learn a useful language more quickly, easily, and effectively than does the 'lip reading and speech' method now taught in the cities. For children who are born deaf, attempts to teach only lip-reading-and-spoken-language often end in cruel disappointment (see p. 331). **The 'special educators' in the cities could learn a lot from these villagers.**

Disabled children – if allowed – often show great imagination and energy in figuring out ways to move about, communicate, or get what they need. Much of what they do is, in effect, 'therapy', artfully adapted for and by each child.

With a little help, encouragement, and freedom, the disabled child can often become her own best therapist. One things is certain: she will make sure her therapy is 'functional' (useful), always changing it to meet her immediate needs. A disabled child, like other children, instinctively knows that life is to be lived NOW and that her body and her world are there to be explored, used, and challenged. **The best therapy is built into everyday activities: play, work, relationship, rest, and adventure.**

The challenge, then, for health workers and parents (as well as for therapists), is to look for ways that children can get the 'therapy' they need in ways that are easy, interesting, and functional.

This takes imagination and flexibility on the part of all those working with disabled children, but mostly, it takes understanding. When family members clearly understand the reasons for a particular therapy and the basic principles involved they can find many imaginative ways to do and adapt that therapy.

'Physical therapy' to improve control of the head, strength of the back, and use of both arms and hands together:

(a) in a city clinic



(b) in a village home



Appropriate therapy helps the child to enjoy himself, be useful, and take part with others, while mastering the skills for daily living.

Physical therapy and rehabilitation techniques have been developed mostly in cities. Yet most of the world's disabled children live in villages and farms. Their parents are usually very busy growing the food and doing the chores to keep the family fed and alive from day to day. In some ways, this makes home therapy more difficult. But in other ways **it provides a wide range of possibilities for exciting therapy in which the child and his family can meet life's needs together.**

Here is a story that tells how therapy can be adapted to village life.

Meena, lives in a small village on a river. She has cerebral palsy. When she was 4 years old, she was just beginning to walk.

But her knees bumped together when she tried to take steps. So she did not try often. Also, her arms and hands were weak and did not work very well.

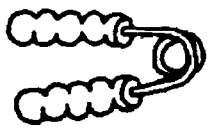


Her family saved money and took Meena to a rehabilitation centre in the city. After a long wait, a therapist examined her. He explained that Meena needed to stretch the muscles on the inner side of her thighs, so her knees would not press together as much.

He recommended that her parents do special exercises with her, and that they buy a special plastic seat to hold her knees wide apart.



He said she also needed exercises to strengthen and increase the control of her hands and arms.

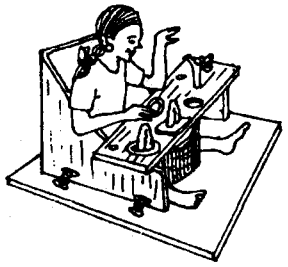


He suggested buying her some special toys, game boards, and aids to practice handling and gripping things.

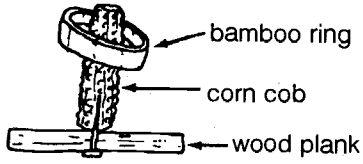
Meena's family could not afford these costly things. So back in her village her father used whatever he could find to make similar aids at low cost. First he made a special seat of sticks.



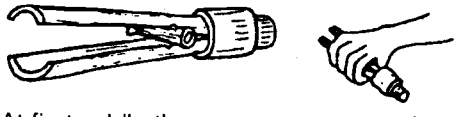
Later he made a better seat with pieces of wood, and an old bucket to hold her legs apart.



Then, using a board, corn cobs and rings cut from bamboo, he added a small table so that she could play games to develop hand control.



He also made a hand exerciser out of bamboo.



At first, while they were strange and new, Meena used her special seat and played with her special toys. But soon, she got bored and stopped using them. She wanted to do the things that other children did. She wanted to go with her father and brother to the cornfield. She wanted to help her mother prepare food and wash the clothes. She wanted to be helpful and grown up.

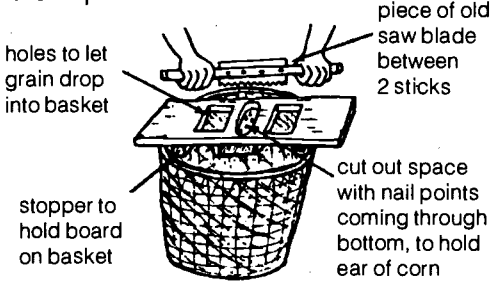
(story continued on next page)

So she broke her special toys and refused to sit in her special seat. Her parents were furious with her - and she loved it! She would sit for hours with her knees together and her legs bent back. Walking began to get more difficult for her, so she did not walk much.



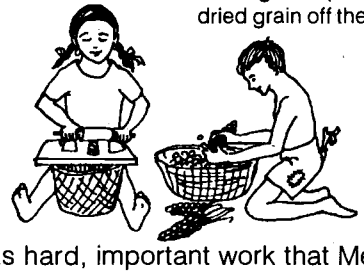
Her parents than visited a small rehabilitation centre in a neighboring village. The Village team suggested that they look for new ways to help Meena keep her knees apart and improve control of her arms and hands - ways that would be exciting and help her to develop and practice useful skills together with the rest of her family. Here are some of the ideas that Meena and her parents came up with:

When she was good (and sometimes even if she was not) her father would let her help shell corn with him and the other children. Because she had trouble holding the corn and snapping off the grain with her fingers. her father made a special holder and scraper.



The basket between her legs held her knees apart, and the shelling of the corn strengthened her arms, gave her practice gripping, and improved her coordination and control.

shelling corn (taking the dried grain off the cobs)



It was hard, important work that Meena found she could do. And she loved it!

Meena's mother sometimes invited her to help wash the clothes at the river. Meena would sit at the river's edge with a big 'washing rock' between her legs. She would wash the clothes by squeezing and beating them against the rock just like her mother.



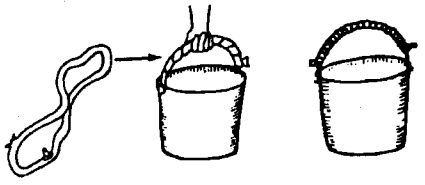
The rock kept her knees apart and the squeezing and banging strengthened her hands and improved her control. But what mattered was getting the clothes clean. It was hard work. But she found it easy-and fun!

Coming back from the river, Meena just had to walk. It was too far to crawl. And besides, she had to help her mother carry back the washed clothes. This was hard, but she tried hard, and could do it!



Carrying the pails of clothes helped her learn to walk without bending and jerking her arms so much.

To help Meena grip the handle of the pail easier, her father wrapped a long strip of old bicycle inner tube very tightly around the handle. But when Meena's hand sweated, the smooth rubber got slippery. So her father wound a thin rope around the rubber. This way, Meena could hold it better.



As time passed she learned how to carry a bucket of clothes on her head - then a bucket of water. To do this took a lot of practice with balance and control of movement. She just had to keep her legs farther apart to keep her balance.

Her mother was almost afraid to let her try carrying the water. But Meena was stubborn - and she did it! Meena also discovered that if she floated a gourd dipper (or a big leaf) on top of the water, it helped keep the water from splashing out.



So, by trying different things, Meena's family, and Meena herself, learned ways to create therapy and aids that were effective, useful, and enjoyable.

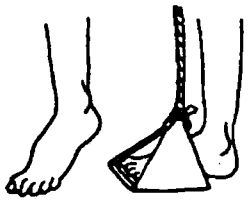
Meena did learn to walk better, and to use her hands and arms to do many things. But this took a long time. Sometimes she would try something that was too hard, and almost give up. But when her little brother would say she could not do it, she would keep trying until she succeeded.

Even when Meena liked doing something, because she was a child she would get bored and not keep doing it for long. Her parents always had to look for new ways for her to get her therapy. It became a challenge and a game for them, too.

Of course, Meena loved horses. So her father made her a rocking horse out of old logs, branches of trees, and a piece of rope for a tail.



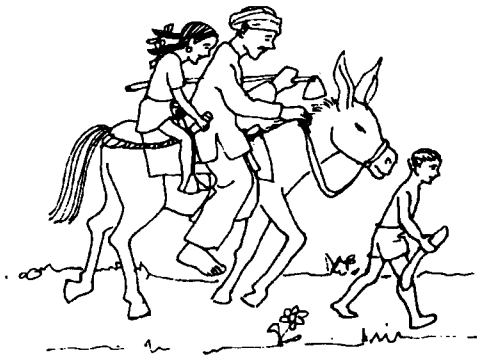
Her father noticed that she was beginning to walk on tiptoe, so he made special stirrups for the rocking horse. With these, when she rocked, her feet stretched up in a more normal position.



The rocking horse kept her knees apart, strengthened her hands, and helped her improve her balance. Meena loved her horse and sometimes rocked for an hour or more. When she got off, it seemed she could walk better.

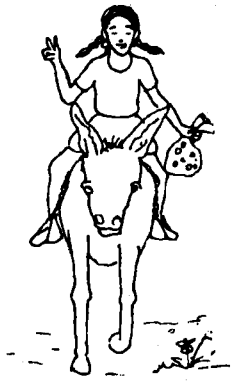
After Meena had learned to ride the rocking horse, she wanted to ride the real thing. She begged and begged. So one day her father let her ride with him to the cornfield on his donkey. He suggested she ride in front of him where he could hold her. But she insisted on riding behind, like other children do.

So he fixed some stirrups and let her ride behind. Her legs were spread wide and she hung on tightly. It was excellent therapy—but nobody called it that.



In the cornfield she helped her father and brother clean the weeds out from among the young corn plants. That was good for the young plants-and for her, too! But after several trips to the cornfield on the donkey with her father, Meena begged him to let her ride alone. He was nervous, But he let her try.

She could do it - and what confidence it gave her! Soon Meena was preparing lunch for her father and brother and taking it to them in the cornfield - all by herself. Now she found she could do many other things she never thought she could. Although she was still awkward, and at times had to look for special ways to do things, she found she could do almost anything she wanted or needed to.



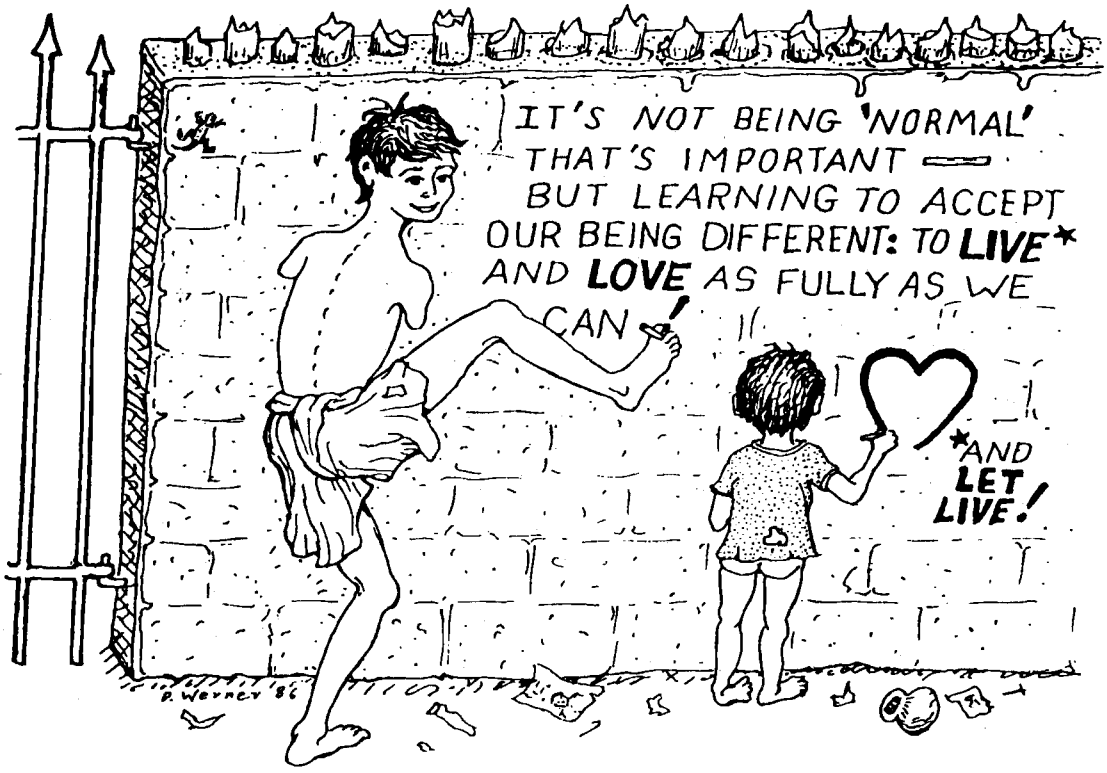
The example of Meena's 'therapy' cannot and should not be copied – but instead, learned from. In fact, the story suggests that **no approach to rehabilitation should be copied exactly.** Our challenge is to understand each child's needs, and then to look for ways to **adapt her rehabilitation to both the limitations and possibilities within her family and community.** We must always look for ways to make therapy functional and fun.

Recently some 'appropriate technology' groups have tried to adapt standard 'rehabilitation aids' to poor rural communities. However, many of their designs are modeled fairly closely after the same old city originals, using bamboo and string instead of plastic and aluminium. Some of these low-cost designs are excellent. But more effort is needed to make use of the unique possibilities for rehabilitation and therapy that exist in the village, farm, or urban slums.

Meena's family did just this. The basket of corn, the washing rock, the rocking horse, and the donkey all became 'therapy aids' to help Meena spread her spastic legs, and at the same time, to take part in the life of her family and community.

But not every family shells corn in baskets, washes clothes on rocks, or has a donkey. And not every disabled child has Meena's needs and strengths. So we repeat:

We should encourage each family to observe the specific needs and possibilities of their disabled child, to understand the basic principles of the therapy needed, and then to look for ways to adapt the therapy to the child's and family's daily life.



CHAPTER 2

Ideas for Sharing Information from This Book

Most of the information in this book will be useful to health workers and rehabilitation workers in villages as well as in urban slums who see many disabled children. ***Some*** of the information will also be useful for the family of a disabled child. However, a family with one disabled child will usually not need, or be able to afford this whole book. It has information about so many different disabilities, that parents may have difficulty finding the information that applies to their child.

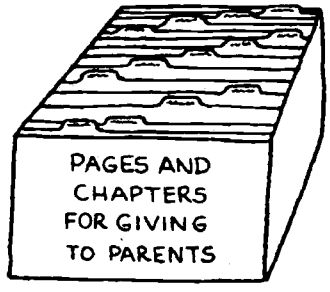
Also, learning from a book is often not the best way to learn something. A lot of methods, aids, and exercises can be learned more easily from other persons, through watching and through guided practice. But after a village worker has taught parents how to do certain exercises, or shown them an example of a homemade aid, **printed instruction sheets with clear drawings can be a big help.** Sometimes they can make the difference between whether the recommendations are followed at home, or not.

There are certain pages or parts of this book that you may want to give to families after you explain and teach to them selected exercises or activities. For example, to the family of a girl with arthritis, you may want to give some of the "Exercise Instruction Sheets" at the end of Chapter 43, and the "Information Sheet on Aspirin" on p. 154. You may also want to give them pages from Chapter 16 on arthritis, and to mark the exercises and activities that are important to their child.

To the family of young child who is slow to develop, you may want to give pages from the chapters on child development and early stimulation activities (Chapters 35 and 36). For a more advanced child you could give the family material from the chapters on self-care (Chapters 37 to 40).

Depending on the interest and reading ability of the family, you may want to give them a whole chapter (or chapters) about their child's disability. For example, the chapters on cerebral palsy (Chapter 9) or deafness (Chapter 31). An older child who is paralyzed from a broken back might appreciate having a copy of the chapter on spinal cord injury, Letting him and his family take home the chapters on pressure sores and urine and bowel control could even save his life! His family may also want to take home plans for making a low-cost wheelchair, to see if the carpenter and blacksmith in their village could make one.

In Project PROJIMO in Mexico, the village rehabilitation team keeps a big file box with copies of the different pages and chapters that they have found most useful for giving to families. (In fact, the exercise sheets at the end of Chapter 43 were originally prepared separately to give to families. Later, we decided to include them in this book.)



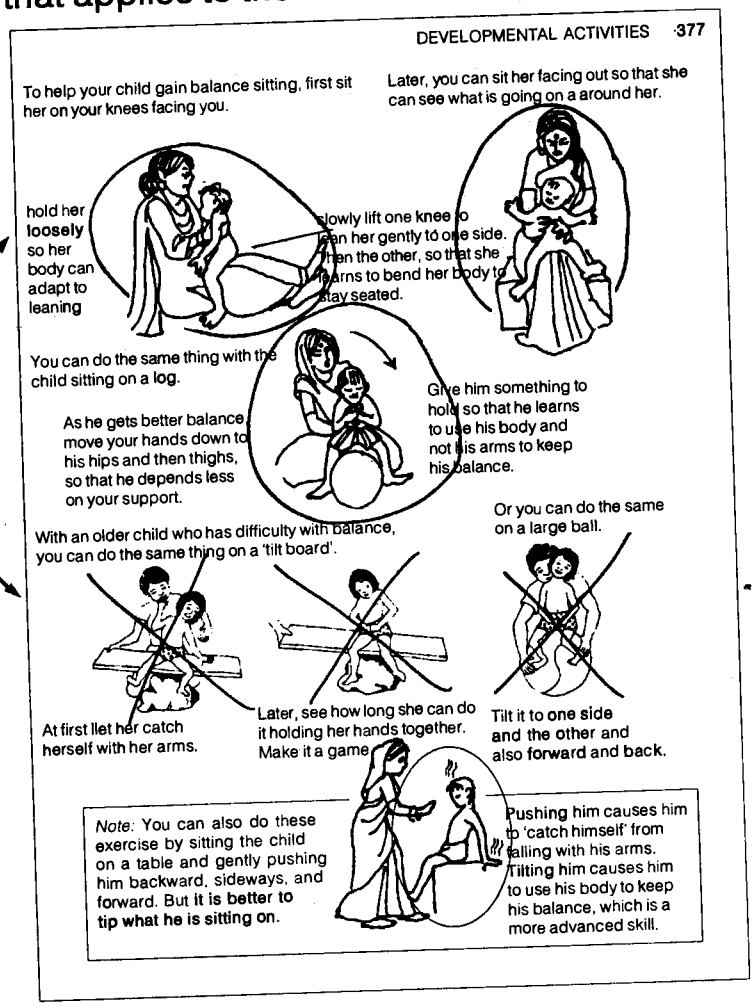
Suggestion: Keep a file of pages, chapters, and information sheets to give to families.

Marking the information that applies to the child

On any page or chapter that you give to parents, some of the information or suggestions will apply more than others to their child.

We suggest that you **circle the activities or suggestions that would be most helpful to the child in his present condition or level of development.** You could also put an "X" through anything that should not be done or might be harmful for that child.

Here is an example. If the child is spastic and beginning to sit, the first 3 activities on p. 377 can help her to improve balance and to develop controlled body movement. So circle these. The next 3 activities will still be too difficult and could increase *spasticity*. Put an "X" through these so the family does not do them.



Making copies of pages can be costly. Or you may have to go a long way for them. Also, there will be times when you want to give a family written suggestions or drawings that you have not copied in advance.

Perhaps some of the children or young people who are at the village center, either for rehabilitation or as learners-and-workers, can help trace drawings from the books. If they have some artistic skill, they can make the drawings larger, or make the child in the drawing look like the child that they are to be used with.*



Minerva, a girl with polio who is working and learning at PROJIMO, helps adapt drawings from this book to the needs of specific children.

*Ideas for drawing and for copying drawings at larger size are in *Helping Health Workers Learn*, p. 12-1 to 12-21.

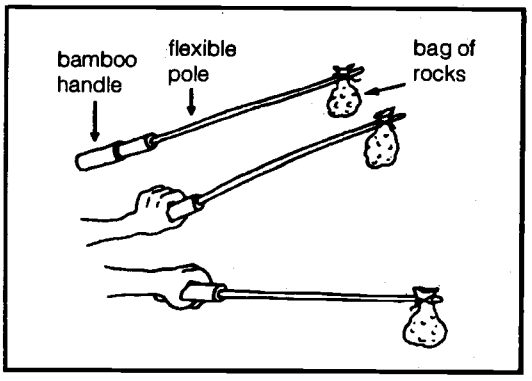
If someone prepares a set of large drawings in advance, perhaps a disabled child who visits the village center can trace the drawings of exercises he needs to do at home. Giving the child this responsibility from the start makes it more likely that he will do the exercises at home.

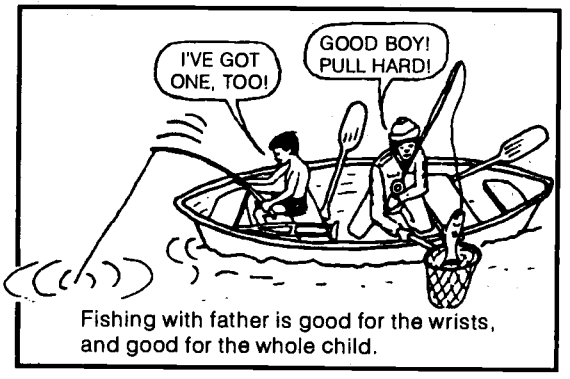
If you make your own 'hand out' sheets (instead of just copying pages of this book) you can use the local language and villagers' way of saying things. You can also adapt the drawings to the hair style and dress that people feel 'at home' with.

Whatever you do, try to keep both your language and drawings **simple** and **clear**. Avoid unfamiliar words.

Also, try to **think of ways of adapting exercises or activities to the local situation.**

For example, **suppose you live in a fishing village,** and want to make copies of a drawing showing an aid for strengthening the wrist. Instead of just copying a method like this from a book, you might add a drawing like this one. This will encourage parents to think of ways to do exercises that involve their child in the life and action of their community.





Fishing with father is good for the wrists, and good for the whole child.

Remember: Written pages and drawings can be a big help, but they should not be a substitute for teaching and showing. To help a family understand activities or exercise that are needed:

1. First show and explain.
2. Guide them in doing it until they do it right and understand why.
3. Then, give them the instruction sheet and explain the main points.

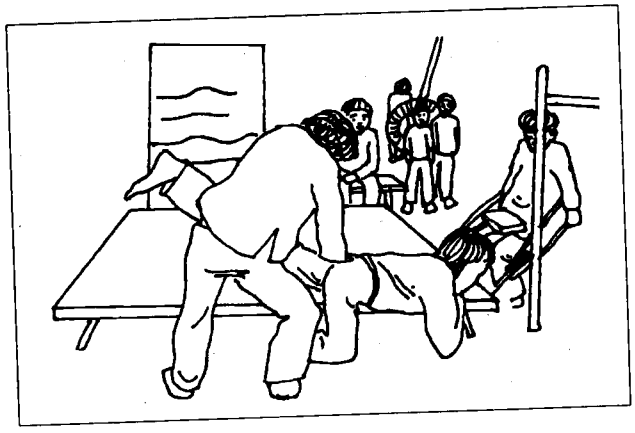
These steps are explained with examples and drawings on p. 470.

As much as you can, try **not** to use this book for giving exact instructions on how to do things. Instead, encourage everyone to use it as a source of ideas, in order to figure out better ways to help **their children** lead fuller lives and manage better **in their communities.**

REMEMBER . . .

One of the best ways to share information from this books is to:

1. **SHOW** other people how to do things



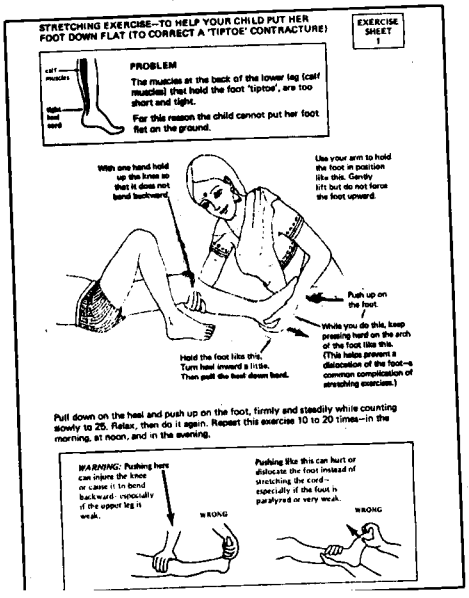
Village rehabilitation workers and family members learn in an outdoor class. Here they practice a hip-stretching exercise. Behind them, drawings on the blackboard show which muscles are stretched.

2. Then help them **LEARN BY DOING** it themselves - under your guidance.



Teaching a village health worker how to stretch a tight heel cord (see p. 93.)

3. And to help them remember, give them a **DRAWING** or **INSTRUCTION SHEET.**



STRETCHING EXERCISE--TO HELP YOUR CHILD PUT HER FOOT DOWN FLAT (TO CORRECT A 'TIPTOE' CONTRACTURE)

EXERCISE SHEET 1

PROBLEM

The muscles at the back of the lower leg (calf muscles) that hold the foot 'tiptoe', are too short and tight.

For this reason the child cannot put her foot flat on the ground.

With one hand hold up the knee so that it does not bend backward.

Use your arm to hold the foot in position like this. Gently lift but do not force the foot upward.

Push up on the foot.

While you do this, keep pressing hard on the arch of the foot like this. (This helps prevent a dislocation of the foot--a common complication of stretching exercises.)

Hold the foot like this. Turn heel inward a little. Then pull the heel down hard.

Pull down on the heel and push up on the foot, firmly and steadily while counting slowly to 25. Relax, then do it again. Repeat this exercise 10 to 20 times--in the morning, at noon, and in the evening.

WARNING: Pushing here can injure the knee or cause it to bend backward - especially if the upper leg is weak.

WRONG

Pushing like this can hurt or dislocate the foot instead of stretching the cord - especially if the foot is paralyzed or very weak.

WRONG

IMPORTANT: Try to help people to understand not only **what** to do, but also **why.** Perhaps you can hold classes using information from this book. Try to combine **hands-on practice** with discussion of **principles and reasons**

CHAPTER 3

Prevention of Disabilities

Because this is a book on ***'rehabilitation'***, it is mostly about children who are already disabled. However, Preventing ***disabilities*** is also very important. For this reason, in most chapters on specific disabilities, we include suggestions for preventing them.

Notice that **we place the discussion of prevention at the end of each chapter,** not at the beginning. This is because people are usually not concerned about disability until someone they love becomes disabled. then their first concern is to help that person. *After* we have helped a family to do something for their disabled child, we can interest them in ways to prevent disability in other members of the family and community.

We mention this because when health professionals design community programs, often they try to put prevention first – and find that people do not show much interest. However, when a group of parents comes together to help their disabled children, after their immediate needs are being met, they may work hard for disability prevention.

For a community program to be successful, start with what the people feel is important, and work from there.

To prevent disabilities, we must understand the causes. In most parts of the world, **many causes of disability relate to poverty.** For example:

- **When mothers do not get enough to eat** during pregnancy, often their babies are born early or underweight. These babies are much more likely to have cerebral palsy, which is one of the most common severe disabilities. Also, some birth defects are related to poor nutrition during the first months of pregnancy.

- **When babies and young children do not get enough to eat,** they get infections more easily and more seriously. Diarrhea in a fat baby is usually a mild illness. But in a very thin, malnourished baby, diarrhea often leads to serious dehydration, high fever, and sometimes brain damage with fits or cerebral palsy.

- **Poor sanitation and crowded living conditions,** together with poor food, make diseases such as tuberculosis – and the severe disabilities it causes-much more common.

- **Lack of basic health and rehabilitation services** in poor communities makes disabilities more common and more severe. Often secondary disabilities develop that could be prevented with early care.

To prevent the disabilities that result from poverty, big changes are needed in our social order. There needs to be fairer distribution of land, resources, information, and power. Such changes will happen only when the poor find the courage to organize, to work together, and to demand their rights. **Disabled persons and their families can become leaders in this process.** Only through a more just society can we hope for a long-term, far-reaching answer to the prevention of disabilities caused by poverty.

Although the most complete prevention of disabilities related to poverty depends on social change, this will take time. However, more immediate actions at family, community, and national levels can help prevent some disabilities. For example,

- **Polio**, in certain situations, can be prevented through ***vaccination***. (However, effective vaccination depends on much more than good vaccine. See the box.) →

In places where vaccination is not available or not fully effective, families and communities can help to lower the chance of ***paralysis*** from polio in other ways:

- ♦ by breast feeding their children as long as possible (see p. 82).
- ♦ by not letting their children get unnecessary injections (see p. 20 to 22).

Why, since a good vaccine exists, is there still so much polio in so many countries?

EFFECTIVE VACCINATION DEPENDS ON MANY FACTORS:

TECHNICAL Production and supply of safe, effective, vaccine.



EDUCATION People must understand the value of vaccination and want to cooperate. Health workers must know how important it is to keep polio vaccine frozen.

ECONOMIC (Cost of vaccine and of getting it to the children.) Leaders in poorer countries must decide that stopping polio is worth the expense.



POLITICAL Vaccination programs are most successful where the government fairly represents the people and has their full participation in country-wide vaccination campaigns.

MANAGEMENT Knowledge of needs, planning, transportation, and distribution of the vaccine.

ETHICAL (Honesty and good will) Doctors, health workers, and citizens must try to see that vaccine reaches ***all*** children. (In some countries, some doctors throw vaccines away and fill out false reports, and health inspectors do not care enough to try to stop what is happening.)

KEEPING POLIO VACCINE FROZEN (in many countries, 1/3 of vaccines are spoiled by the time they reach the children.)

- **Brain damage** and **fits** can become less frequent if mothers and midwives take added precautions during pregnancy and childbirth, and if they vaccinate children against measles. (See p. 121.)

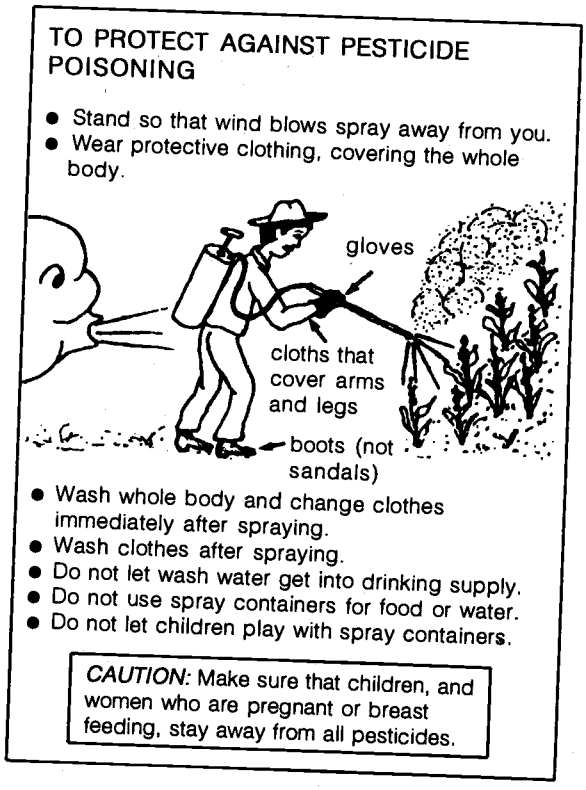
- Some **birth defects** and **mental retardation** can be prevented if mothers **avoid most medicines** during pregnancy, and spend the money they save on **food.**

- **Spinal cord injury** could be greatly reduced if fathers would spend on **education and community safety** what they now spend on **alcohol and guns.**

- **Leprosy** could mostly be prevented if people would **stop fearing and rejecting persons with leprosy.** By being more supportive and encouraging early home treatment, the community could help prevent the spread of leprosy, since persons being treated no longer spread it. (See p. 253.)

- **Blindness** in young children in some countries is caused by not eating enough food with **vitamin A.** Again this relates to poverty. However, many people do not know that they can prevent this blindness by feeding their children dark green leafy vegetables, yellow fruits, or even certain weeds and wild fruit. Also, some kinds of **deafness** and **mental retardation** can be prevented by using **iodized salt** during pregnancy (see p. 331 and 342).

- **Disability caused by poisons in food, water, air, or workplace.** The recent, common, worldwide use of chemicals to kill insects and weeds has become a major health problem. Often farmers and their children use these pesticides without any knowledge of their risks, or of the precautions they should take. As a result, many become paralyzed, blind, or disabled in other ways. For example, heart disease, cancer, brain, kidney and liver damage.



- **The Handigodu Syndrome**
  In the Shimoga and Chikmanglur districts of Karnataka, a crippling joint disease has been reported in an endemic form among people who eat crabs and fish from fields sprayed regularly with the pesticides, Malathion and Endrin.

  Amongst children, the disease has not only crippled but also inhibited their growth. More and more children are being born with congenital abnormalities. This is known as the Handigodu Syndrome.

- **Epilepsy**
  The use of BHC (Benzene Hexa Chloride) for preserving food grains led to an epidemic of epilepsy in the Lakhimpur Kheri district of Uttar Pradesh.

  People suffered from sudden convulsive seizures that racked the body. They heard whistling noises in the ears, saw flashes of colored lights and suffered from giddiness and headaches.

  To prevent these problems, people need to learn about the dangers, not only to themselves and their children but to animals, birds, land, and to the whole 'balance of nature'. Less dangerous ways to control pests give better results over time. Laws are also needed to prohibit the most dangerous products and to provide clear warnings.

- **Radiation** also causes disabilities. Women living near the atomic power plant in Rawat Bhatta, Rajasthan, have been known to give birth to babies without fingers and genital organs; joined toes and abnormally sized heads. Many children born in the coastal areas of Kerala have been severely affected by the highly radioactive thorium bearing mineral, ***monazite***. Monazite is found in the black beach sands of this area. The disabilities range from Down Syndrome, cerebral palsy, mental retardation and hearing impairment to cancer and other genetic disorders.

- **Poisonous foods** in some areas are a major cause of disability. In parts of India, thousands of farm workers who are paid with a poisonous variety of lentils suffer paralysis from **'lathyrism'**. The poor know the danger but have nothing else to eat. Fair wages and less corruption are needed to correct this situation. (See Chapter 34).

- **Fluoride poisoning** (fluorosis), mainly from drinking water, is a common cause of bone deformities (knock-knees) in parts of India and other places. Public health measures are needed to provide safe water. (See Chapter 11, p.133.)

The 4 biggest causes of 'crippling' in India, affecting over 2 million people, are reported to be polio, iodine deficiency, fluorosis, and lathyrism. Given the political will, all could be completely prevented!

- **Dangerous work conditions,** poisons in the air, and lack of basic safety measures result in many disabilities. These include burns, amputations, blindness, and back and head injuries. In some countries, the use of asbestos for roofs or walls in schools, work places, and homes causes disabling lung diseases. Strict public health measures and an informed, organized people are needed to bring improvements.

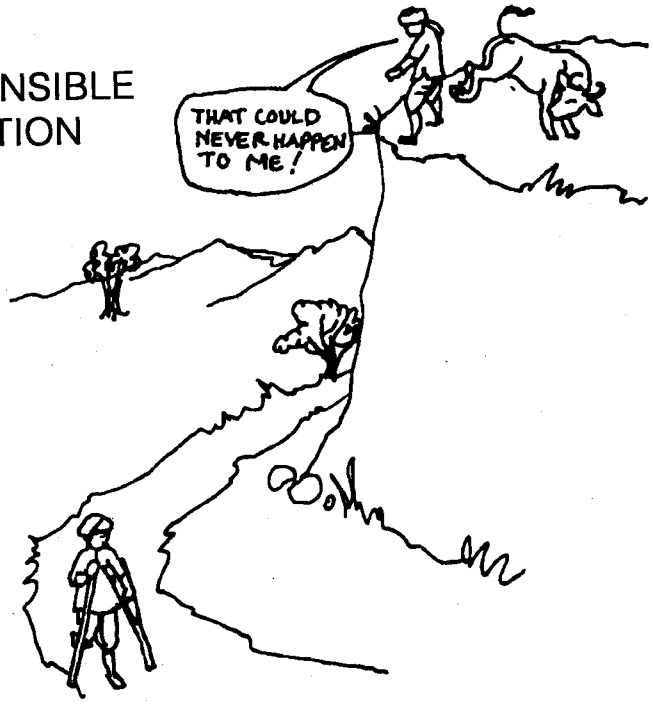
- **Certain dangerous medicines,** known to sometimes cause disabilities, are now prohibited in the countries that make them, but are still sold in other countries. For example, diarrhea medicines containing clioquinol caused thousands of cases of blindness and paralysis in Japan. (good books discussing dangerous medicines in poor countries is ***Bitter Pills*** by Diana Melrose. See p. 773, ***Banned and Bannable*** Drugs – VHAI and ***Where There is no Doctor***, p.525 to 530.)

The high cost, overuse, and misuse of medicines in general adds greatly to the amount of poverty and disability in the world today. better education of both doctors and people, and more effective international laws are needed to bring about more sensible supply and use of medicines.

WHO SHOULD BE RESPONSIBLE FOR DISABILITY PREVENTION

Notice that many of the specific preventive measures we have discussed, just like the more general social measures, depend on increased awareness, community participation, and new ways of looking at things. These changes do not just happen. They require a process of education organization, and struggle led by those who are most deeply concerned.

Most able-bodied persons are not very concerned about disability or trying to prevent it. Often people think, "Oh, that could never happen to me!"-until it does.



Disability can affect everybody, and sometime in our lives it usually does.

* ***Note :*** Although too much fluoride is harmful, some is necessary for healthy bones and teeth. In some areas fluoride needs to be removed from drinking water; in other areas it needs to be added.

Those who are most concerned about disability are usually disabled persons themselves and their families. Based on this concern, they can become leaders and community educators for disability prevention.

They can do this in an informal, person-to-person way.
For example,



Or disabled children and families can join together to form prevention campaigns. In one village, mothers put on short plays to inform the whole community about the importance of breast feeding and vaccination. (See p. 82.) In Project PROJIMO, Mexico, disabled rehabilitation workers have helped to vaccinate children in remote mountain villages.

In PART 1 of this book, where we discuss different disabilities, we also include basic information on prevention. **We hope that those of you who use this book for children who are already disabled, will also work actively towards disability prevention.**

THE "KNOCK ON EACH DOOR" CAMPAIGN

- September 1990 in the city of Bombay.

The Bombay Municipal Corporation was very worried that the number of immunized children in the large number of slums in the city was very low. The existing facilities provided for immunisation were just not being used. Something had to be done - but it had to be done in a way that ensured the total participation and involvement of communities where the children were to be immunized.

Three organisations, The Bombay Slum Dwellers Federation, which includes the Railway Slum Dwellers Federation, The Pavement Dwellers Association and others; The Mahila Milan, a federation of women's collectives from pavements and slum settlements; and 'Saadak Chaap', a federation of street children — joined hands to work towards getting children in their communities immunized. Together, they aimed to reach out to over 3,00,000 households in poor settlements. The campaign was coordinated by Spark (a non governmental organisation working for women's rights) and UNICEF Bombay.

In the slums of Bombay, posters and banners were printed and wall painting made, all in the different languages that different communities used.

These were hung and pasted in places **where everyone has to go** — toilets, water taps, ration shops and outside the Urban Health Center's wall. Everyday, when people went to the toilets or the water taps – they were reminded of the fact that they must get their children immunized.

The children from Saadak Chaap enacted plays spreading the message. All through the campaign they wore T-shirts with messages printed on them – so that wherever they went, on trains, to their work, people read the message.

At another level, leaders of the Federation located 50 young and committed people, residents of poor settlements who wished to contribute to their own communities. These young people combed every street and every house of the communities allocated to them. **They knocked on each door.** Local leaders had already prepared the community for this activity. This was important, as wherever the young people went, women quoted the message of the local leaders. They were ready to get their children immunized. In houses close to each other several women answered for one another.

Each child who needed immunisation was given a card. **The mother was directed to the nearest health post and told which day to go there with the card and baby.**

Two weeks later, the same volunteer went back and checked whether the mother and child had gone to the health centre. In this way, members of different organizations were able to work together with people in the community. Together, they were able to help prevent children from getting disabled.

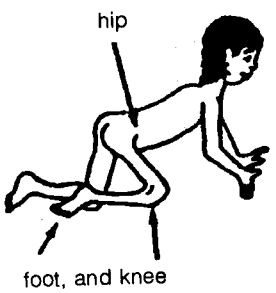
PREVENTING SECONDARY DISABILITIES

So far we have talked mainly about preventing original or 'primary' disabilities, such as polio or spinal cord injury. But the prevention of 'secondary' disabilities is also very important, and is one of the main concerns of rehabilitation.

By 'secondary' disabilities we mean further disabilities or complications that can appear after, and because of, the original disability.

For example, consider a child with polio or cerebral palsy who at first is unable to walk. She gradually loses the normal range-of-motion of joints in her legs. Shortened muscles, called *'contractures'*, keep her legs from straightening. This secondary disability may limit the child's ability to function or to walk even more than the original paralysis:

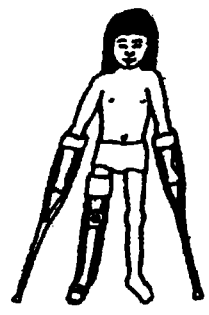
This child, after polio, gradually developed contractures in her



The contractures (not the original paralysis) kept her from being able to stand or walk.



If the contractures had been prevented through early and continued range-of-motion exercises, the child would have been able to stand and walk.



Most contractures can be corrected. But it may take a long time and a lot of expense-perhaps even surgery. It is far better to :

PREVENT CONTRACTURES BEFORE THEY START

Because contractures develop as a common complication in many disabilities, we discuss them in a separate chapter (chapter 8). Range-of-motion exercises to help prevent and correct contractures are described in Chapter 43. Use of plaster casts to correct contractures is described in Chapter 60.

Many other secondary disabilities will also develop unless preventive measures are taken. Some examples are **pressure sores** in children with spinal cord injury (see Chapter 24), **spinal curve** in a child with a weak back or with one leg shorter than the other (see Chapter 20), **head injuries** due to fits (see p. 285). Preventive measures for many other secondary disabilities are discussed in the chapters on the specific disabilities.

In several places we discuss problems or **disabilities that are commonly caused by medical treatment or orthopedic aids.** For example,

- The **medicine for fits,** phenytoin, produces serious swelling of the gums in some children. This can partly be prevented by brushing the teeth regularly.
- **Crutches** that press hard under the armpit can damage nerves and gradually paralyze the hands. Shorter crutches, or lower-arm crutches (like those shown above) prevent this problem. (see p. 481.)
- **Surgery** is sometimes done to remove contractures that actually help a child to move or function better. So worse difficulties result. The benefits or possible harm of surgery should be carefully evaluated **before** it is done. (See p. 643.)
- Some braces or aids that help a child at first, may later actually hold her back. (see p. 638 to 642.)

To prevent these mistakes, it is essential to **evaluate the needs of each child carefully, and repeat evaluations periodically.** We must take great care to prevent further disability caused by treatment.

The first responsibility of a rehabilitation worker or parent, like the healer, should be to:
DO NO HARM

In addition to secondary disabilities that are physical, others may be psychological or social (affecting the child's mind, behavior, or place in the community).

Some disabled children develop serious **behavior problems.** This is often because they find their bad behavior brings them more attention and 'reward' than their good behavior. Chapter 41 discusses ways that parents can help prevent tantrums and bad behavior in disabled children.

The biggest secondary handicap for many disabled children (and adults) usually comes from the lack of understanding and acceptance by other people. PART 2 of this book talks about how the community can be involved in taking a more active, supportive role in relating to the disabled and helping them to meet their needs. In PART 2 we also discuss what disabled persons and their families can do, in the community, to promote better understanding and prevent disability from becoming a serious handicap.

Prevention of secondary disability is a basic part of rehabilitation.

THE NEED FOR MORE SENSIBLE AND LIMITED USE OF INJECTIONS



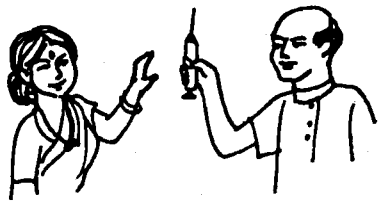
The overuse and misuse of medicines in the world today has become a major cause of health problems and disabilities. This is partly because medicines are so often prescribed or given wrongly (for example, certain medicines taken in pregnancy can cause birth defects, see p. 139). And it is partly because both poor families and poor nations spend a great deal of money on overpriced, unnecessary, or dangerous medicines. The money could be better spent on things that protect their health-such as food, vaccinations, better water, and more appropriate education. Some medicines, of course, when correctly used are of great importance to health But most are not. **Of the 30,000 medicinal products sold in most countries, the World health Organization says that only about 250 are needed.**



In most of the world, doctors, health workers, and the people make giving and getting injections too big a part of health care.

In many countries, **injections have become the 'modern magic'.** People demand them because doctors and health workers often prescribe them, and doctors and health workers prescribe them too often because people demand them.

I HAVE FAITH IN INJECTIONS BECAUSE MY DOCTOR PRESCRIBES THEM.



I PRESCRIBE SO MANY INJECTIONS BECAUSE MY PATIENTS HAVE FAITH IN THEM.

Giving injections with an unclean needle or syringe is a common cause of ***infection***. Sometimes these infections can lead to **paralysis**, or **spinal cord injury** (see the story on p. 225), or death.

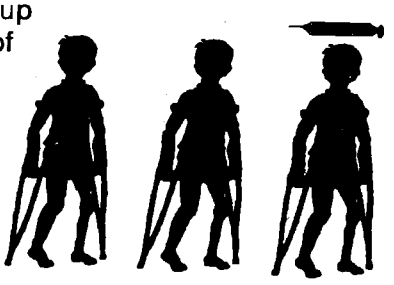
Also, some injected medicines can do harm. **Dangerous allergic reactions, poisoning,** and **deafness** are sometimes caused by injecting certain medicines often when they are not needed.

Overuse by doctors and midwives of **injectable hormones** to speed up childbirth and 'give force' to the mother has become a major cause of babies born with **brain damage, cerebral palsy,** and **fits** in many countries.



This child was injected with a needle that was not sterile (clean). The dirty needle caused an infected abscess (pocket of pus) that in time burst and drained. The child had been injected for a cold. It would have been better to give him no medicine at all.

The disability most often caused by injections is **paralysis from polio.** Some experts say that **each year up to 2 million children are paralyzed by polio because of injections. Nearly all of these injections are given when they are not needed.**



1 out of every 3 cases of paralysis from polio is caused by injections.

It happens like this. Children who are infected by the polio virus usually only have signs of a bad cold or 'flu'. Most get well in a few days, without developing paralysis. But the risk of paralysis increases if the child's muscles are injured or irritated. Injections of any kind of medicine irritate the muscles. Messages from the irritated muscles travel up the nerves to the ***spinal cord,*** and cause changes that let the polio virus produce paralysis.

Unfortunately, when children develop a cold or 'flu' caused by the polio virus, their parents often take them to a doctor or health worker for an injection. Many times the result is paralysis, which is usually worse in the leg on the side that was injected. Many people used to think that paralysis in a leg after an injection was caused because the needle 'hit a nerve'. We now know that in most cases the paralysis was caused by polio. because it was brought on or 'provoked ' by an injection, this is called 'provocation polio'.

It is very important that mothers-and doctors-remember that **Children should not be given injections when they have signs of a cold with fever of 'flu'. it might be polio, and an injection could bring on paralysis.**

If injections are given to children only when they are really needed, millions of cases of polio could be prevented.

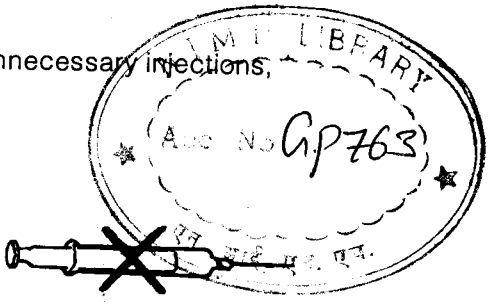
The **worldwide epidemic of unnecessary injections** each year sickens, kills, or disables millions of persons, especially children. An international campaign is needed to re-educate doctors, health workers, traditional healers (many of whom also now overuse injections), and the people themselves.

Combating misuse and overuse of medicines is as important a preventive measure as is vaccination, clean water, or the correct use of latrines.

Health workers, school teachers, and community organizers should all work to 'de-mystify' or take the magic out of injections, and to help people always to **weigh the possible risks and benefits** before using any medication.

For skits and ideas on teaching people about the danger of unnecessary injections, See ***Helping Health Workers Learn,*** Chapters 18, 19, and 27.

Note: **When used correctly, certain injected medicines are important to health.** Vaccinations,including those that are injected, are very important to protect a child's health and prevent disability. However, **to avoid paralysis from polio,** it is best not to give vaccinations (immunizations) or any other injection when a child has a fever or signs of a cold. This could be a mild polio infection, and giving an injection could cause paralysis.



AVOID UNNECESSARY INJECTIONS

WAR AS A CAUSE OF CHILD DISABILITY

In today's wars, more civilians than soldiers are killed or disabled, and most are women and children. In World War One, only 5 percent of persons killed or injured were civilians. At least 3 times as many people are injured as are killed.

The increased poverty and 'hard times' caused by war also lead to many disabilities. One-third of the world's children lack adequate food and basic health care. Millions are homeless. Yet world leaders are continuing to spend more and more on arms.

War, terrorism, and torture have become tools of the powerful for economic, political and social control. When the peoples of poor countries dare to get rid of their directors and form popular governments that work toward fairer distribution, the rich, powerful countries often try to destroy those new governments. They pay for terrorism, long wars, and the destruction of schools, health centers, and production. The result is still more poverty, disease, and disability.

To help change this situation, we disabled persons of the world must join with all who are disadvantaged or treated unfairly, to struggle for a new, more truly human, world order.



Nicaraguan child disabled by a 'Contra' bomb. The Contras are rebel troops supported by the United States Government to overthrow the new government in Nicaragua. (Photo by Marc Krizack, Links)

Terrorism is too often fought with terrorism. During the U.S. attack on Libya in April, 1986, bombs hit a school for disabled children. Such actions do not stop terrorism; they merely kill and disable innocent persons.

"AN EYE FOR AN EYE WILL MAKE THE WHOLE WORLD BLIND."
-Mahatma Gandhi.

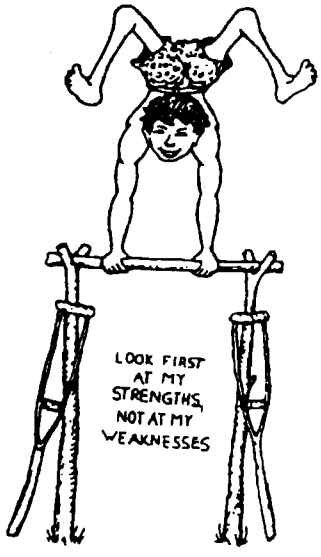
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Examining and Evaluating the Disabled Child

CHAPTER 4

To decide what kind of special help, if any, a disabled child may need, first we need to learn as much as we can about the child. Although we may be concerned about her difficulties, we must always try to **look at the whole child**. Remember that:

> **A child's *abilities* are more important than her *disabilities*.**



The aim of rehabilitation is to help the child to function better at home and in the community. So when you examine a child, try to **relate all your observations to what the child can do, cannot do, and might be able to do.**

What a child is and does depends partly on other persons. So we must also look at the child's abilities and difficulties in relation to her home, her family, and her village or neighborhood.

To evaluate a child's needs, try to answer these questions:

- **What can the child do and not do?** How does this compare with other children the same age in your community? Make a checklist of the basic activities performed generally by ordinary children in the community. Different checklists can be prepared for different age groups. You can keep up dating it as you learn more from the experiences of different families.

- What **problems** does the child have? How and when did they begin? Are they getting better, worse, or are they the same?

- In what ways are the child's **body, mind, senses,** or **behavior** affected? **How does each specific problem affect what the child does?**

- What **secondary problems** are developing? (Problems that result after and because of the original problem.)

- What is the **home situation** like? What are the **resources and limitations within the family and community** that may increase or hold back the child's possibilities?

- What are the **expectations** of the child and the family? It is important to consider the expectations of the parents in the rehabilitation of their child. After all they are the main caretakers of the child. For example if there is parent with a mentally handicapped child who is not toilet trained and the parents feel that it is of utmost importance because they are finding it very difficult to help the child, then toilet training becomes a major need of both the child and the parent.

- In what way has the child **adjusted to her disability,** or learned to manage?

To find the answers to these questions, a health or rehabilitation worker needs to do 3 things:

1. **Observe the child** carefully-including her interaction with the family and with other persons.
2. **Take a 'history'.** Ask the parents and child (if old enough) for all information they can provide. Obtain medical records if possible.
3. **Examine the child** to find out how well and in what way different parts of her body and mind work, how developed they are, and how much they affect her strengths, weaknesses or problems.

BE SURE TO LOOK AT THE WHOLE CHILD-NOT JUST THE DISABILITY

Observation of the child can begin from the first moment the health worker or rehabilitation worker sees the child and her family. It can begin in the waiting area of a village center, the home, or the street, and should continue through the history-taking, examination, and follow-up visits. Therefore, we do not discuss 'observation' separately, but include it with these other areas.

It is usually best to **ask questions BEFORE beginning to examine the child** - so that we have a better idea what to look for. Therefore, we will discuss history-taking and then examination. But first a word about keeping records.

RECORD KEEPING

For a rehabilitation worker who helps many children, writing notes or records can be important for following their progress. Also, parents of a disabled child may find that keeping simple records gives them a better sense of how their child is doing.

Six sample RECORD SHEETS are on pages 39 to 43, 52, 360, and 361. You can use these as a guide for getting and recording basic information. But you will want to follow with more detailed questions and examination, depending on what you find.

Sample RECORD SHEETS included in this book	RECORD SHEET number	page
Child history	1	39 and 40
Physical examination	2	41
Tests of nervous system	3	42
Factors affecting child development	4	43
Measuring a child's progress	5	52
Child development chart	6	360 and 361

Sheets 1 and 2 will be useful for most disabled children. Sheets 3,4 and 6 are for children who may have brain damage or seem slow for their age. Sheet 5 is a simple form for
evaluating the progress of children 5 years old or older.

HISTORY TAKING

On pages 39 and 40 you will find a record sheet for taking a child's history. You can use it as a guide for the kinds of questions it is important to ask. (Of course, some of the questions will apply more to some children than others, so ask only where the information might be helpful.)

When asking questions, we rehabilitation workers must always remember that **parents and family are the only real 'experts' on their child.** They know what she can and cannot do, what she likes and does not like, in what ways she manages well, and where she has difficulties.

However, sometimes part of the parents'knowledge is hidden. They may not have put all the pieces of knowledge together to form a clear picture of the child's needs and possibilities. The suggestions in this chapter, and the questions on the RECORD SHEETS, may help both rehabilitation workers and parents to form a clearer picture of their child's needs and possibilities.

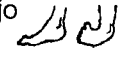
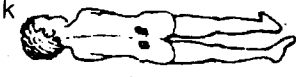
Rehabilitation workers and parents can work together to figure out the child's needs.

EXAMINING THE DISABLED CHILD

After finding out what we can by asking questions, our next step is to examine the child. In as friendly a way as possible, we carefully observe or test what parts of the child work well, what parts work poorly, and how this affects the child's ability to do things and respond to the world around him.

CAUTION: Although we sometimes examine separately different aspects of the child's body and mind, our main purpose is **to find out how well the child's body and mind work together as a whole: what can the child do and not do, and why?** This information helps us decide how to help the child to do things better.

In examination of a disabled child, we may check on many things:

- **The senses:** How well does the child see?  hear?  feel? 
- **Movement:** How well does the child move or control her movements? 
- **Form and structure:** How well formed, deformed, or damaged are different parts of the body: the jo  the backbc  and sk 
- **Mind, brain, and nervous system:** How much does the child understand? How well do different parts of the body work together? For example, balance or eye-to-hand coordination. 
- **Developmental level:** How does the child do things, compared to other local children of her age?

In addition, **a complete** physical examination would include checking the health of **systems inside the body.** Although this part of the examination, if needed, is usually done by health workers, rehabilitation workers need to know that with certain disabilities inner body systems may also be affected. Depending on the disability, these may include:


the breathing system (respiratory system)


the body's cleaning system (urinary tract)


the heart and blood system (circulation system)


the food processing system (digestive system)

Rehabilitation workers need to work in close cooperation with health workers.

A detailed examination of ***all*** a child's parts and functions could take hours or days. Fortunately, in most children this is not necessary. Instead, **start by observing the child in a general way.** Based on the questions you have already asked and your general observations, try to **find anything that seems unusual or not quite right. Then examine in detail any body parts or functions that might relate to the disability.**

Part of the art of examining a child is KNOWING WHEN TO STOP. It is important to check everything that might help us understand the child's needs. But it is equally important to win the child's confidence and friendship. Too much examining and testing can push any child to the point of fear and anger. Some children reach their limit long before others. So we must learn how much each child can take — and try to examine the child in ways that she accepts.

Some children require a much more complete examination than others. For example:

(CP)

Manu lost one hand in an accident 2 years ago, but otherwise seems normal. Probably he will need little or no physical examination other than to see how he uses his arms, stump, and hand. You will also want to check how much he can do with his other hand, with only his stump, and when using both together.



The Physical Examination From (RECORD SHEET 2 on p. 41) is probably the only examination form you need to fill out.

However, it would be wise to learn about how Manu's family and others treat him now, and how he feels about himself and his ability to do things. Does he keep his stump hidden when he is with strangers? With family members? What are his hopes and fears? You can write this information on the back of the form.

Ila is 2 years old and still does not sit by herself, She has strange uncontrolled movements. She does not play with toys or respond much to her parents.



Ila seems to have many problems.

We will need to check:

- how well she sees and hears.
- how strong, weak, or stiff different parts of her body are.
- in what ways her development is slow (what she can do and not do).
- how much she understands.
- signs of brain damage, and how severe.
- her sense of balance and position.
- what positioning or support gives her better control and function.

It may take weeks or months of repeated examining and testing to figure out all of Ila's difficulties, and how to best help her to function better. It could be a mistake to try to do all the needed examining at one time.

To record all the useful information on a child like Ila, you will find RECORD SHEETS 1,2,3,4, and 6 helpful.

Examining techniques: Winning the child's confidence

Depending on how you go about it, the physical examination can help you become a child's friend or turn you into his enemy. Here are a few suggestions:

- **Dress as one of the people,** not as a professional. White uniforms often scare a child — especially if at some time he was injected by a nurse or doctor.
- Before starting the examination, **take an interest in the child as a person.** Speak to *him* in a gentle, friendly way. *Help him relax.* Touch him in ways that show you are a friend.
- Approach the child from the same height, not from above. (Try to have your head at the same level as his.)
- Start the examination with the child sitting or lying **on mother's lap, on the floor, or wherever he feels most safe and comfortable.**



- Try to **make the examination interesting and fun** for the child. Turn it into a game whenever possible. For example:

  When you want to test child's 'eye-to-hand coordination' (for possible balance problems or brain damage) you might make a game out of having the child touch the nose of a doll. Or have her turn on a flashlight (torch) by pushing its button

  Also, when he begins to get restless, stop examining for a while and play with him, or let him rest.

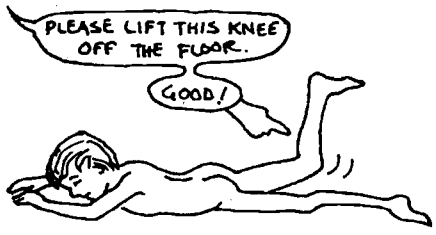




It is best to examine a child when he is well-rested, well-fed, **and in a** 'good mood' – **and when you are, too.** (We know this will not always be possible.)

- When a child is weaker or has less control on one side than the other,

  first test the stronger side, **and then the weaker side.**





By testing the good side first, you start by giving the child encouragement with what he can do well. Also, if the child does not move the weaker side, you will know it is because he cannot, and not because he does not understand or is not trying.

- As you examine the child, **give her lots of praise and encouragement.** When she tries to do something for you and cannot, praise her warmly for trying.

- Ask her to **do things she can do well and not just the things she finds difficult,** so that she gains a stronger sense of success.

- Try to observe the child while she is immersed in an activity. For example see how she eats her food. This will tell you a lot about her abilities.



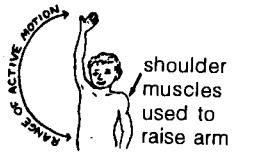
TESTING RANGE OF MOTION OF JOINTS AND STRENGTH OF MUSCLES

Children who have disabilities that affect how they move often have **some muscles that are weak** or 'paralyzed'. As a result, they often do not move part of their bodies as much as is normal.

Loss of strength and active movement may in time lead to a stiffening of joints or shortening of muscles (contractures, **see chapter 8**). As a result, **the affected part can no longer be moved through its complete, normal range of motion.**

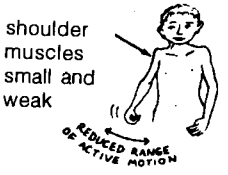
ACTIVE MOVEMENT

Normally the shoulder muscles can raise the arm until it is straight up.



Lifting the arm like this with the arm's own muscles is called **ACTIVE MOTION.**

When the shoulder muscles are paralyzed, the child can no longer actively lift his arm.

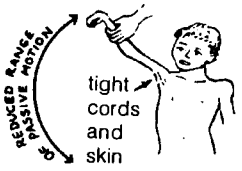


PASSIVE MOVEMENT

At first the paralyzed arm can be lifted straight up with help. This is called **PASSIVE MOTION.**



Unless the normal range of motion is kept through daily exercises, the passive range of motion will steadily become less and less.



Now the arm cannot be raised straight up, even with help.

In the physical examination of a child with any weakness or paralysis of muscles, of joint pain, or scarring from injuries or burns, it is a good idea to **test and record both RANGE OF MOTION and MUSCLE STRENGTH of all parts of the body that might have contractures or be affected.** There are 2 reasons for this:

- Knowing which parts of the body have contractures or are weak, and how much, can help us to understand why a child moves or limps as she does. This **helps us to decide what activities, exercises, braces, or other measures may be useful.**
- Keeping accurate records of changes in muscle strength and range of motion can help tell us if certain problems are getting better or worse. Regular testing therefore **helps us evaluate how well exercises, braces, or other measures are working,** and whether the child's condition is improving, and how quickly.

For testing range of motion and muscle strength, it helps to first know what is normal. You can practice testing non-disabled, active persons. They should be of the same ages as the disabled children you will test. Age matters because babies are usually weaker and have much more flexible joints than older children. For example:



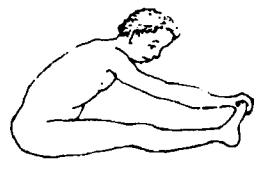
A baby's back and hips bend so much he can lie across his straight legs.



A young child bends less but can usually touch his toes with his legs straight.



Around 11 to 14 it is harder to touch toes. His legs grow faster and become longer than his upper body.



Later, upper body growth catches up with legs. He can again touch toes more easily.

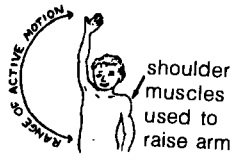
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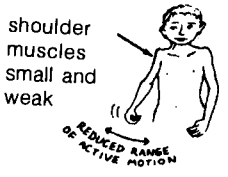
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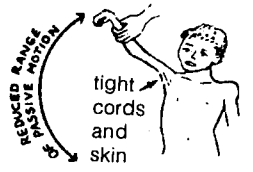


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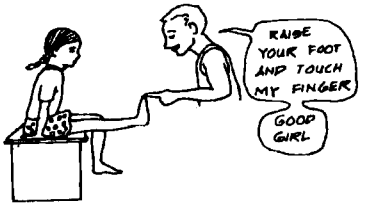
In different children (and sometimes in the same child) you may need to check range of motion and strength in the hips, knees, ankles, feet, toes, shoulders, elbows, wrists, hands, fingers, back, shoulder blades, neck, and jaw. Some joints have 6 or more movements to test: bending, straightening, opening, closing, twisting in, and twisting out. See, for example, the different hip movements (range-of-motion exercises) on p.468 in Chapter 43.

To test both 'range of motion' and 'strength', first check 'range of motion'. Then you will know that when a child cannot straighten a joint, it is not just because of weakness.

Range-of-motion testing: Example:

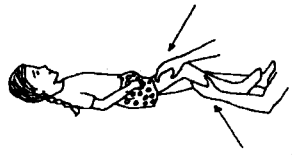
Knee

1. Ask the child to straighten it as much as she can.

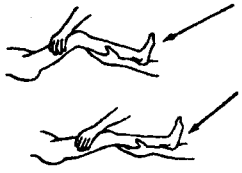


2. If she cannot straighten it all the way, gently see how far you can straighten it **without forcing.**

With your hands, support the joint on each side as you straighten it.



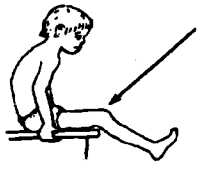
(CP) 3. If at first the joint will not straighten, keep trying with **gentle continuous pressure** for 2 of 3 minutes.



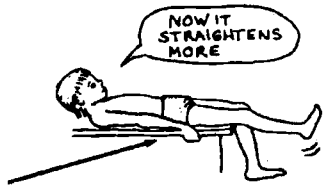
If it still does not straighten, the range of motion is reduced. This is usually because of a **contracture** (see Chapter 8).

If it gradually straightens, **spasticity** (muscle spasms) may be what makes it difficult (see p. 89). (If it stops before it straightens completely, contractures may also be developing.)

4. If a joint will not straighten completely, try with the child in different positions.



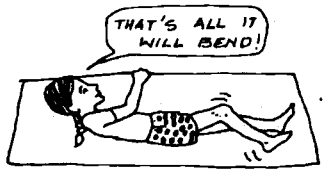
For example, a knee often does not straighten as much with the hips bent as with the hips straight.



For this reason, each time you test range of motion to measure changes, **be sure the child is in the same position.**

(CP) Position affects how much certain joints straighten or bend. This is true in any child, but especially in a child with **spasticity** (see pages 114 to 117).

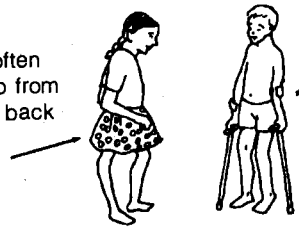
5. In addition to checking how much a joint straightens, check **how much** it bends.



If joints are kept straight and never bent, they may stiffen or develop contractures that do not let them bend. (This can happen with joint infection, arthritis, and other conditions, or when a joint is kept in a cast for a long time.)

6. Also check for **too much** range of motion.

A child who walks on a weak leg often 'locks' her knee backward to keep from falling. In time, the knee stretches back more and more, like this.



The same thing can happen to the child with weak arms who uses crutches (or crawls).

Usually the best positions for checking range of motion are the same as those for doing range-of-motion and stretching exercises. These are shown in Chapter 43.

For methods of measuring and recording range of motion, see Chapter 5.

Precautions when testing for contractures

Testing range of motion of the **ankles, knees,** and **hips** is important for evaluating many disabled children. We have already discussed knees. Here are a few precautions when testing for contractures of ankles and hips.

Ankle



normal upward bend

Test the range of motion with the knee as straight as it will go.



Feel the tight heel **cord** here.

With the knee bent, the foot will usually bend up more. But for walking, we need to know how far it bends with the knee straight.



Note: To check ankle range of motion in a child with spasticity:

CP

With his body and knee straight, if may be hard to bend the ankle.



So first bend his neck, body, and knees and then slowly bend up the ankle.



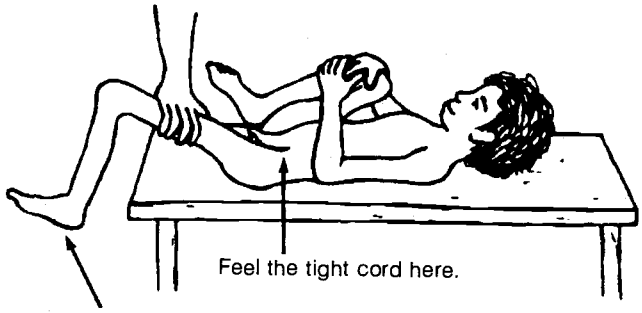
Then slowly straighten his knee while keeping the ankle bent.



Other precautions – for testing ankle range of motion are on p. 471.

Hip

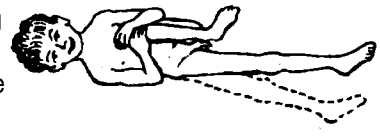
To check how far the hip joint straightens, have the child hold his other knee to his chest, like this, so that his lower back is flat against the table. If his thigh will not lower to the table without the back lifting, he has a bent-hip contracture. (See p. 89.)



Feel the tight cord here.

If the knee will not straighten, test him with his leg over the edge of a table.

CAUTION The hips will often straighten more at an angle to the body. So be sure to lower the leg in a straight line with the body, or you can miss contractures that need to be corrected before the child can walk.



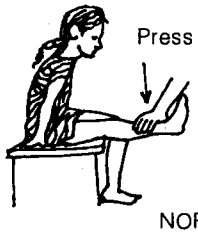
RIGHT

WRONG

Muscle testing

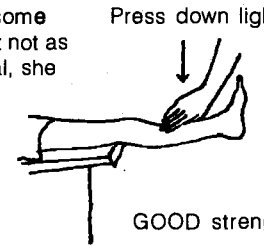
Muscle strength can be anywhere normal and zero. Test it like this:

If the child can lift the weight of leg all the way, press down on it, to check if she can hold up as much weight as is normal for a girl her age. If she can, her strength is NORMAL.



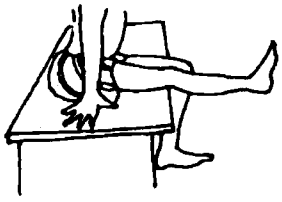
NORMAL strength

If she can hold. **some extra weight**, but not as much as it normal, she rates GOOD.



GOOD strength

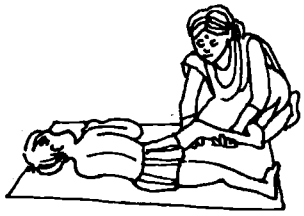
If she can just hold up the weight of her leg, but no added weight, she rates FAIR.



FAIR strength

If she cannot hold up the weight of her leg, have her lie on her side and try to straighten it. If she can, she rates POOR.

POOR strength



If she cannot straighten her knee at all, put your hand over the muscles as she tries to straighten it. If you can feel her muscles tighten, rate her TRACE.

Muscles move, but not leg:

TRACE strength





No muscle movement:

ZERO strength

Test the strength of all muscles that might be affected. Here are some of the **muscle tests that are most useful** for figuring out the difficulties and needs of different children.

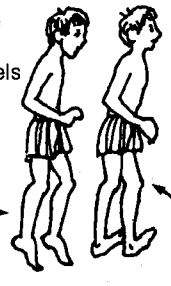
> ***Note:*** These tests are simple and mostly test the strength of groups of muscles. ***Physical therapists*** know ways to test for strength of individual muscles.

Ankle and Foot

DOWN UP BEND IN BEND OUT



If the child can walk, see if she can stand and walk on her heels and her toes.



NORMAL calf muscle

NORMAL foot-lift muscle

Note: Some times when the muscles that normally lift the feet are weak, the child uses his toe-lifting muscles to lift his foot.

If he lifts his foot with his toes bent up, like this.



see if he can lift it with his toes bent down, like this.



Also notice if the foot tips or pulls more to one side. This may show 'muscle imbalance', (See p. 88.)

EXAMPLES OF REASONS FOR TESTING

1. If strength to lift up the foot is WEAK and strength to push down is STRONG, tiptoe contractures may develop-unless steps are taken to prevent them. (See p. 471.)



2. An ankle with POOR or very uneven strength may be helped by an ankle brace. But if strength is FAIR, exercise may strengthen it-and a brace may weaken it more!



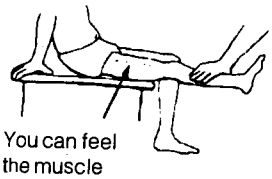
3. Lifting the foot with only the toe muscles may lead to a high-arch deformity.



To learn about which muscles move body parts in different ways, as you test muscle strength, feel which muscles and cords tighten.

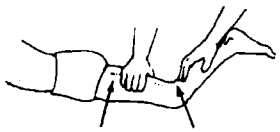
Knee

STRAIGHTEN



You can feel the muscle tighten on top of the thigh.

BEND



Feel the muscles tighten on the back of the thigh.

Feel the tight cords pull here.

EXAMPLES OF REASONS FOR TESTING

1. POOR or NO strength for straightening knee may mean an above-knee brace is needed.

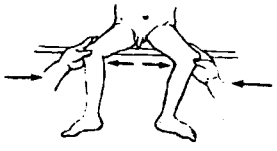


2. Stronger muscles in back of the thigh than in front can lead to a bent-knee contracture.

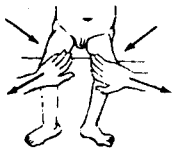


Hips

OPENING



CLOSING



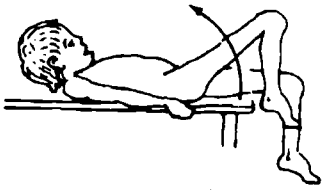
ROTATING HIP OUT (and leg in)



ROTATING HIP OUT (and leg in)

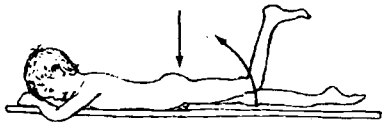


BENDING

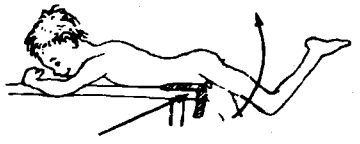


STRAIGHTENING

Feel the butt muscles tighten.



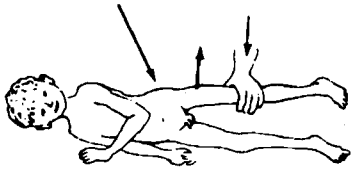
If the hip has contractures, test with legs off and of table.



padding

SIDEWAYS LIFT

Feel the side-of-hip muscles tighten here.



Note: Weak hip muscles sometimes lead to dislocation of the hip. Be sure to check for this, too. (See p. 175.)

Testing side-of-hip muscles is important for evaluating why a child limps or whether a hip-band may be needed on a long-leg brace.

TEST FOR WEAK SIDE-OF-HIP MUSCLES IN THE CHILD WHO CAN STAND

Have the child stand on the weaker leg.

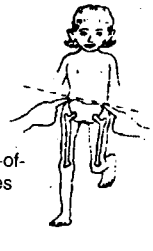
NORMAL

The child stands straight. The hip tilts up on the lifted leg.



weak side-of-hip muscles

The hip tilts down on the lifted side.



NOT NORMAL

Or the child shifts his whole weight so it balances over the weak hip.



This child dips to the side on each step of the weak leg.

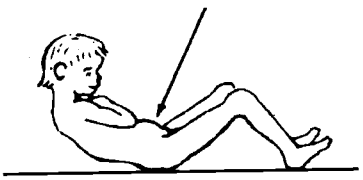
(This is often seen with polio.)

Note: Dipping to one side when walking is caused more by weak side-of-hip muscles than by a shorter leg. But a shorter leg can make dipping worse.

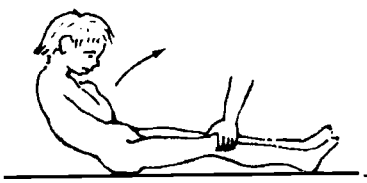
Stomach and Back

To find out how strong the stomach muscles are, see if the child can do 'sit ups' (or at least raise his head and chest).

Sitting up with knees bent uses (and tests) mainly the stomach muscles. Feel stomach muscles tighten.

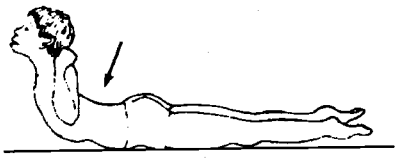


Sitting up with knees straight uses the hip-bending muscles and stomach muscles.



To test the back muscles, see if he can bend backward like this.

Feel the muscles tighten on either side of the backbone. Notice if they look and feel the same or if one side seems stronger.



You can check a child's **trunk control and strength of stomach, back, and side muscles** like this. Have him hold his body upright over his hips, then lean forward and back, and side to side, and twist his body.



If a child's stomach and back muscles are weak, he may need braces with a body support- or a wheelchair.



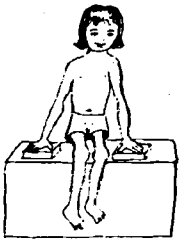
IMPORTANT: Be sure to check for **curvature of the spine** – especially in children with muscle imbalance or weakness of the trunk.

Shoulders, Arms, and Hands

When a child's legs are severely paralyzed but she has FAIR or better trunk strength, she may be able to walk with crutches *if* her shoulders, arms, and hands are strong enough.

Therefore, an important test is this:

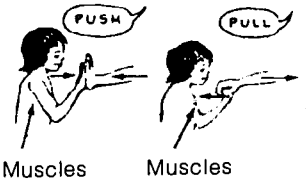
Can she lift her butt off the seat like this?



If she can, she has good chance for walking with crutches.

If she cannot lift herself, check the strength in her shoulders and arms:

ARMS



Muscles tighten here

Muscles tighten here

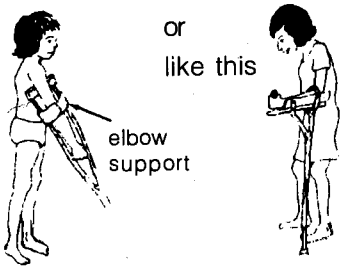
SHOULDERS



like this

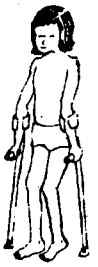
or

like this



If the shoulder pushes down strongly but her elbow-straightening muscles are weak, she may be able to use a crutch with an elbow support.

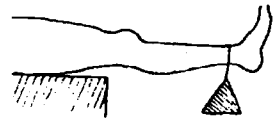
Or, if her elbow range of motion is normal, she may learn to 'lock' her elbow back like this. However, this can lead to elbow problems.



You may want to make a chart something like this and hang it in your examining areas, as a reminder.

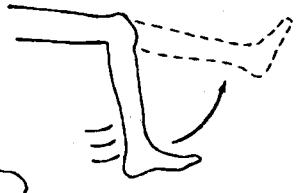
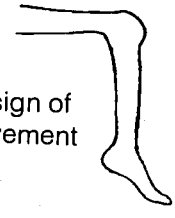
EVALUATING STRENGTH OR WEAKNESS OF MUSCLES

***CAUTION :* To avoid misleading results, check range of motion BEFORE testing muscle strength.**

	Strength rating		Test with the child positioned so that he lifts the weight of the limb.
Strong enough to be useful.	NORMAL (5)	lifts and holds against strong resistance	
	GOOD (4)	lifts and holds against some resistance	
	FAIR (3)	lifts own weight but no more	

In muscle testing, it is especially important to note the difference between FAIR and POOR.

This is because FAIR is often strong enough to be fairly useful (for standing, walking, or lifting arm to eat). POOR is usually too weak to be of much use.

			Test with the child positioned so that he can move the limb without lifting its weight (by lying on his side).
Too weak to be of much use for lifting or bearing weight.	POOR (2)	cannot lift own weight but moves well without any weight	
	TRACE (1)	barely moves	
	ZERO (0)	no sign of movement	

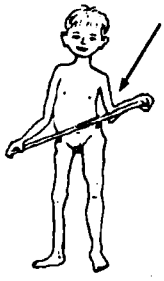
Sometimes with exercise POOR muscles can be strengthened to FAIR; this can greatly increase their usefulness. It is much less common for a TRACE muscle to increase to a useful strength (FAIR), no matter how much it is exercised. (However, if muscle weakness is due to lack of use, as in severe arthritis, rather than to paralysis, a POOR muscle can sometimes be strengthened with exercise to GOOD or even NORMAL. Also, in very early stages of recovery from polio or other causes of weakness, POOR or TRACE strength sometimes returns to FAIR or better.)

Other things to check in a physical examination

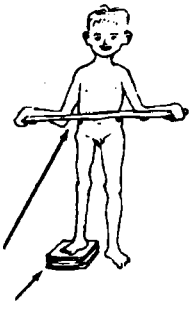
Difference in leg length. When one leg is weaker, it usually grows slower, and becomes shorter than the other leg. An extra thick sole on the sandal might help the child stand straighter, limp less, and avoid curving of the spine. A short leg may also be a sign of a dislocated hip. So it helps to check for, and to measure, difference in leg length.
(For tests, see p. 175 and 176.)

If the child can stand,

look for a tilt of the hip bones,



then raise the foot of the short leg until the hips are level.



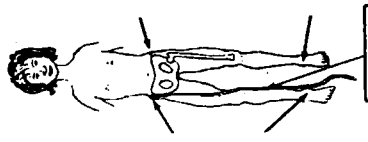
and measure the difference.

If she cannot stand,

have her lie as straight as she can. Feel and then mark, on both sides of her body, the bony lumps

at the top front corner of the hip bone

and on the inner ankle.



Pass tape along inner side of knee.

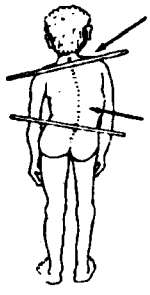
Then measure from here to here with a tape measure or string. Measure each leg and record the difference. If you used a string, just draw lines on your record sheet showing the actual difference in leg length.

LILA'S DIFFERENCE IN LEG LENGTH (LYING DOWN)
JUNE 3, 1986 ———
SEPT 10, 1986 ———
DEC 2, 1986 ———

Curve of the spine

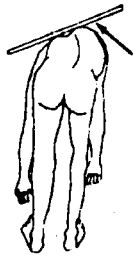
Especially when one leg is shorter or there are signs of muscle imbalance in the stomach or back, be sure to check for abnormal curve of the spine (back bone). The 3 main types of spinal curve (which may occur separately or in combination) are:

Sideways curve (scoliosis)



shoulder higher on side of short leg

Check for weaker muscles on this side of spine.



Have the child bend over.

Check for a rib hump on outer side of curve.

Hunch back, rounded back (kyphosis)

May result from weak back muscles, or poor posture.

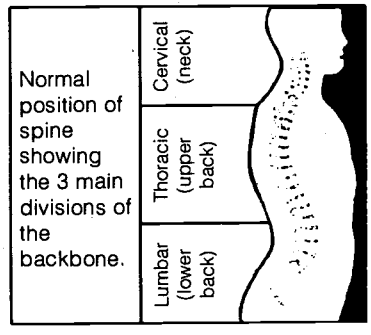


Swayback (lordosis)



May result from weak stomach muscles or bent-hip contractures. (Be sure to check for these.)

Some spinal curves will straighten when a child changes her position, lies down, or bends over. Other spinal curves will not straighten, and these are usually more serious. For more information about examining spinal curve and deformities of the back, see Chapter 20.



EXAMINING THE NERVOUS SYSTEM

Sometimes physical disability results from problems in the muscles, bones, or joints themselves. But often it comes from a problem in, or damage to, the nervous system.

Depending what part of the nervous system it affected, the disability will have different patterns.

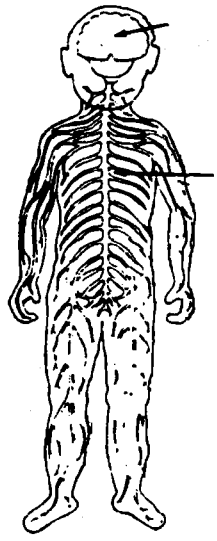
For example, **polio** affects only certain **action nerves** at points in the spinal cord (or brain stem). It therefore affects movement. It never affects sensory nerves, so sight, hearing, and feeling stay normal. (See Chapter 7.)

THE NERVOUS SYSTEM

The nervous system is the body's communication system. The 'central switchboard' is the brain, from which electrical messages run back and forth, to all parts of the body, through 'wires' called nerves.

Sensory nerves bring messages form parts of the body about what the body sees (eyes), hears (ears), smells (nose), and feels (skin).

Action nerves (motor nerves) carry messages to parts of the body, telling muscles to move.



The brain is the main control center of the nervous system.

The 'trunk line' of the nerves is the spinal cord. It runs from the brain down the middle of the spine. Nerves come out from between each back bone and communicate to a part lower down in the body.

A **spinal-cord injury,** however, can damage or cut both the sensory and action nerves, so that both movement and feeling are lost. (See Chapter 23.)

Unlike polio and spinal-cord injury, which come from damage to nerves in the spine, **cerebral palsy** comes from damage to the brain itself. Because any part or parts of the brain may be damaged, any or all parts of the body may be affected: **movement, sense of balance, seeing, hearing, speech,** and **mental ability.** (See Chapter 9.)

Therefore, how completely you examine the workings of the nervous system will depend partly on what disability the child appears to have. If it is fairly clear the disability comes form polio, little examination of the nervous system is needed. But sometimes polio and cerebral palsy can be confused. If you have any suspicion that the disability might be caused by brain damage, you will want to do a fairly complete exam of nervous system function. **Damage to the brain or nervous system can cause problems in any of these areas:**

- seeing (See Chapter 30.)
- eye movement or position (See pages 42 and 371.)
- fits or seizures (epilepsy) (See Chapter 29.)
- balance, coordination, and sense of position (see pages 100 and 119.)
- hearing (See Chapter 31.)
- use of mouth and tongue, and speech (See pages 383 to 385.)
- mental ability; level of development (See pages 337 and 356.)
- feeling (pain and touch) (See pages 41 and 255.)
- unusual or strange behaviors: signs of self-damage (See page 446.)
- muscle tone (patterns of unusual floppiness, tightness, spasms, or movements). (See Chapter 9.)
- reflexes; muscle jerks (See pages 42 and 98.)
- urine and bowel control (See Chapter 25.)

Methods for testing some of these things are included on the next few pages and on the RECORD SHEETS 2, 3, and 4. Other tests that you will need less often, we include with specific disabilities. Refer to the page numbers listed above.

EVALUATION OF A CHILD WHOSE DEVELOPMENT IS SLOW

For the child who cannot do as much as other children do at the same age, a special developmental evaluation may be helpful. Additional information about the child's mother during pregnancy, or any difficulties during or after birth may explain possible causes. Measurement of the distance around the head may show possible causes of problems or other important factors. Repeated head-size measurements (once a month at first) may tell us even more.



For example, a child who has had meningitis (brain infection) at age 1, and whose head almost stops growing from that age on, will probably remain quite retarded. We should not expect a lot. However, if the child's head continues to grow normally, the child may have better possibilities for learning and doing more (although we cannot be sure).



A child who is born with a 'sack on the back' (spina bifida, see p. 189) may have a head that is bigger than average. If the head continues to grow rapidly, this is a danger sign (see p. 43 and 195). Unless the child has surgery, she may become severely retarded or die. If, however, the monthly measurements show that the head has stopped growing too fast, the problem may have corrected itself. She may not need surgery.

RECORD SHEET 4, on page 43, covers additional questions relating to child development, and includes a chart for recording and evaluating head size.

To help the child who is developmentally delayed, you will first want to evaluate her level of physical and mental development. Chapter 35, explains ways to do this.

You can use the Child Development Chart on pages 292 and 293 to find a child's developmental level, to plan her step-by-step activities, and to evaluate and record her progress. We have marked this 2-page chart, RECORD SHEET 6.

RECORD SHEETS

On the next 5 pages are the sample RECORD SHEETS that we discussed on p. 24. You are welcome to copy and use them. However, they are not perfect. They were developed for use by the village rehabilitation team in Mexico, and we are still trying to improve them. Before you make copies, we suggest that you adapt them to meet the needs of your area.

Be sure you have copies made of the RECORD SHEETS you will need before you need to use them.

In addition to the 4 RECORD SHEETS here, you may also want copies of RECORD SHEET 5 "Evaluation of Progress,' page 52, and RECORD SHEET 6, "Child Development Chart," pages 360 and 361.

Note on RECORD SHEET 1 (CHILD HISTORY):

The box at the top of RECORD SHEET 1 is to be filled out after you examine the child. It gives brief, essential information. This will make it easier to find out which disabilities you have seen most often, and to check on what you still need to do for different children.

The last few questions on page 2 of RECORD SHEET 1 are for a study PROJIMO is doing on medical causes of disability. Adapt them to study special concerns in your area.

File Number	TYPE OF DISABILITY	Future action: Date: Done:	RECORD SHEET 1 (page 1)
Code	Movement _____ Deformity _____ Retarded _____ Blindness _____ Deafness _____ Speech _____ Fits _____ Behavior _____ Other _____	___come back again _____ ___refer to specialist _____ ___visit at home _____ ___other _____	
Specific disability if known: _____			

CHILD'S HISTORY (First visit)



Name: _____ Sex:
Date of birth: _____ Address: _____
Age: ____ Weight: _____Height: _____
Mother:_____ _____
Father:_____ Telephone: _____
How did you learn about the program? _____
WHAT IS THE CHILD'S MAIN PROBLEM? _____
_____
_____
When did it begin? _____ How? (Cause?) _____
Other problems? _____
Is the disability improving?_____Getting worse?_____About the same?_____
Explain: _____
How do you hope your child will benefit from coming here? _____
Do other family members or relatives have a similar problem ?_____ who ?_____
Has the child received medical attention_____ what? _____
_____Where? _____
Use any braces or other aids?_____What?_____
Has he used any in the past?_____Explain:_____
How is child's general health? _____
Is he fat?_____ Very thin?_____Other?_____
Hears and sees well?_____Explain:_____
Comment on the child's developmental abilities or difficulties: normal for age?

head control _____ _____
use of hands_____ _____
creeping or crawling _____ _____
standing, walking _____ _____
play _____ _____
feeding or drinking _____ _____
toileting _____ _____
personal hygiene _____ _____
dressing _____ _____

Does the child speak? _____How much or well?_____Began when?_____
What other things can the child do? _____
_____
What things can the child not do? _____
_____
What new skills or abilities would you like to see your child gain?_____
_____

RECORD SHEET 1 (page 2)

Is the child mentally normal?_____
Retarded?_____How severely? _____
Why do you think so: _____
Does the child have fits?_____How often?_____
Describe:_____
Take medicine?_____What?_____
For what?_____Results (good or bad):_____
Behavior normal for age? _____
Behavioral or emotional problems?_____Explain:_____
_____
_____
Goes to school?_____What year?_____
With whom does the child live? _____
Number of brothers and sisters:_____ Ages:_____
Father works?_____At what? _____
Mother works?_____At what?_____
The child seems: well-cared for?_____spoiled or overprotected?_____
neglected?_____happy? _____self-confident? _____ withdrawn? _____
other?_____
Important details of family situation: _____
_____
_____
What has the family done, made, or obtained to help the child function better?_____
_____
Other observations, information or drawings:
(Use an additional sheet if necessary.)
_____
_____
_____
_____
_____
_____
_____
_____
_____

AVERAGE EARNINGS
_____

History of illness	Date
measles	_____
chicken pox	_____
whooping cough	_____
other	_____
_____	_____

Vaccinations:	How many	Dates	Allergies
polio	_____	_____	_____
D.P.T.	_____	_____	_____
measles	_____	_____	_____
BCG (TB)	_____	_____	_____
Other	_____	_____	_____

How much have you spent for your child's disability?_____For what?_____
_____
Were disability or complications caused by improper medical treatment or therapy?_____Explain: _____
FOR CHILDREN WITH POLIO:
Was your child injected within 2 weeks before getting polio?_____
If so, was he or she injected on the side that became most paralyzed?_____

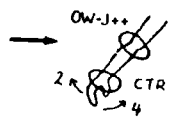
SAMPLE RECORD SHEET FOR PHYSICAL EXAM

RECORD SHEET 2

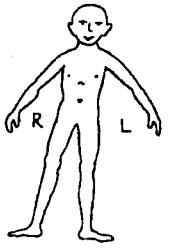
Child's name _____

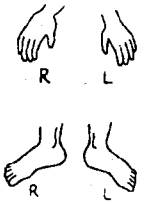
File number _____

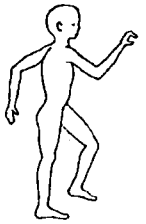
Mark on the drawings where you find the problems. Use lines and circles together with abbreviations shown on this page. For example;



Where necessary, make new drawings on another sheet.







Parts of body affected



L or R_____other_____
(indicate)

OW: Pain OW-J pain in joints OW-M pain in muscles

0 none
\+ little
++ a lot
+++ so much that she does not move it



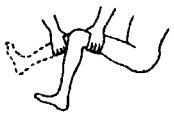
CTR: contractures

____tight muscles do not yield with pressure



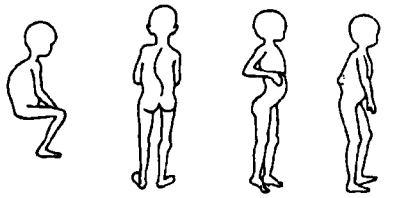
SP: spasticity

____*tight muscles yield slowly with pressure



Spine

hunchback (kyphosis) | sideways curve (scoliosis) | swayback (lordosis) | hard bump (TB?)



Curve fixed____curve can straighten____
(See p. 181.)

Strength or weakness of muscles: Use this code

NORMAL 5 — lifts and holds against strong resistance

GOOD 4 — moves against some resistance

FAIR 3 — lifts own weight but no more



POOR 2 — moves some but cannot lift own weight

TRACE 1 — barely moves

ZERO 0 — no sigh of movement



T: ability to feel, touch, pain, etc.



other

R or L	normal	*reduced	*absent

Problems with

_____ * Eyes or sight. What: _____

_____ * Ears or hearing. What: _____

Deep tendon reflexes:



Right knee
Left knee
Other_____

*nothing 0	*little +	normal ++	*brisk +++	*extreme ++++

HT: hips tilt



R leg shorter____

L leg shorter____ by_____cm

DL: dislocations:



hip _____

knee _____

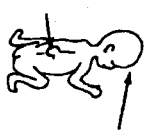
elbow _____

other _____

R	L	from birth	old	new

***Spina bifida**

soft sac



*large head (hydrocephalus)

back already operated ___date ___

head already operated ___date ___

extent of paralysis _____

_____

extent of feeling lost _____

_____

***Spinal cord injury**

what level _____



	Good	Poor	None
Bowel control			
Bladder control			

Other problems

____ * pressure sores
____ * unusual movements
____ * tremors
____ * fits
____ * poor balance
____ * developmental delay

IMPORTANT: This form does not cover all the tests and information you will want to record when examining a child. But other info...

*If you check any problem area marked with a star(*), a more complete check of the nerv...

RECORD SHEET : ADDITIONAL TESTS AND OBSERVATIONS OF THE NERVOUS SYSTEM

RECORD SHEET 3

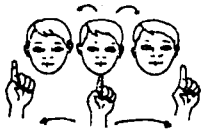
These tests are often not needed but may sometimes be useful when you are not sure if a child has brain damage. For other signs of brain damage, see Chapter 9 on Cerebral Palsy. For tests of seeing and hearing, see p. 541 to 548.

Eye Movement

___ eyes jerk, flutter, or roll up unexpectedly and repeatedly and repeatedly (brain damage, possible epilepsy – p.283).

___ one eye looks in a different direction or moves differently from the other (possible brain damage)

___ move finger or toy in front of eyes from side to side and up and down.



___ eyes follow smoothly normal

___ eyes follow in jumps or jerks (possible brain damage)

Eye to hand coordination

___ moves finger from nose to object and back again almost without error - with eyes open, and also closed (normal)



___ misses or has difficulty with eyes open (poor coordination, poor balance, or loss of position sense)

___ has much more difficulty with eyes closed (loss of position sense)

Body movements

___ awkwardness or difficulty in controlling movements

___ sudden or rhythmic uncontrolled movements

___ parts of body twist or move strangely when child tries to move, reach, walk, speak, or do certain things

(All these may be signs of brain damage; see Chapter 9.)



Details of any of the above: _____

_____

_____

Fits of different kinds (See Chapter 29).

___ sudden loss of consciousness with strange movements,

___ brief periods of strange movements or positions,

___ blank stares, ___ eye fluttering, ___ twitching.

Developmental delay Is the child unable to do many different things that others her age can do? Which? (See Chapter 35).

___ head control
___ use of hands
___ rolling
___ creeping and crawling
___ speech
___ sitting
___ standing and walking
___ sucking
___ eating
___ playing
___ communication or
___ behavior
___ self–care activities

Balance

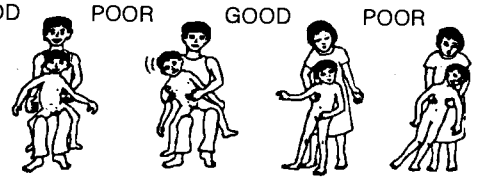
With the child in a sitting or standing position, gently rock or or push him off balance.

___ CHILD DOES NOT TRY TO KEEP FROM FALLING (poor balance – sign of brain damage in child over 1 year)

___ CHILD TRIES NOT TO FALL BY PUTTING OUT HIS HANDS (fair balance)

___ CHILD KEEPS FROM FALLING by correcting body position (good balance)

GOOD POOR GOOD POOR



Balance test for the older, more stable child

Have child stand with feet together.

___ balance difficulty with eyes open – may be brain damage (or muscle-joint problem)

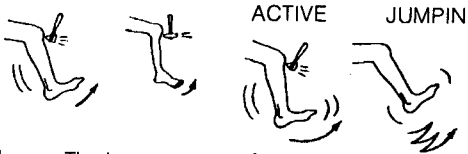
___ balance difficulty much greater with eyes closed (probably nervous system damage)



'Knee jerks' and other 'muscle jump' reflexes

With the leg relaxed and partly bent, tap the cord just below the knee cap

NORMAL REDUCED OVER ACTIVE KEEPS JUMPING



The knee jumps a little

The leg moves very little or not at all. Typical of polio, muscular dystrophy,and other floppy paralyses.

A slight tap causes a **big jump**. Typical of spasticity from cerebral palsy, spinal cord injury, and other brain or damage.

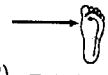
One tap causes the limb to jerk many times Happens with spinal cord injury and some cerebral palsy.



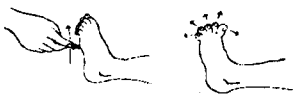
You can also tap the heel cord and other cords near joint.

Great toe reflex

Stroke the foot toward the toe with a somewhat pointed object (like a pen).



NORMAL NOT NORMAL (in a child over 2)



toes bend up

This is a sign of brain or spinal cord damage (Babinski's sign) May occur in a normal child under

RECORDS OF FACTORS POSSIBLY AFFECTING CHILD DEVELOPMENT

(mainly for children with possible brain damage or developmental delay)

RECORD SHEET 4

Added history

Was the child born before 9 months?_____ at how many months?)_____
Was the child born smaller or thinner than normal?_____ weight at birth?_____
Was the birth of the child normal?_____ slow or difficult? _____
Explain:_____
Did the child seem normal at birth?_____ If not, describe problems: delayed breathing?_____
very floppy?_____ other?_____
Did the mother have problems in pregnancy?_____ German measles_____at_____months.
Other?_____. Medicines or drugs during pregnancy:_____ what? _____
Age of mother _____ and father _____ at time of child's birth.

Physical exam

Does the child show signs of brain damage? (Use RECORD SHEETS 3 and 4.)
What? _____
Does the child show signs of Down syndrome (mongolism)?_____
What? (wide, slanted eyes_____, crease in hand _____, other_____. See p.339.)
Other physical signs, possibly related to retardation _____
Does the child's head seem smaller _____ or larger _____ than normal?
Distant around head?_____ cm. Difference from normal _____cm.
Average at her age (from chart) _____ cm. Difference from average _____ cm.

Record of the child's head size

On the chart put a dot where the up-and-down line of the child's age crosses the sideways line of her head size:



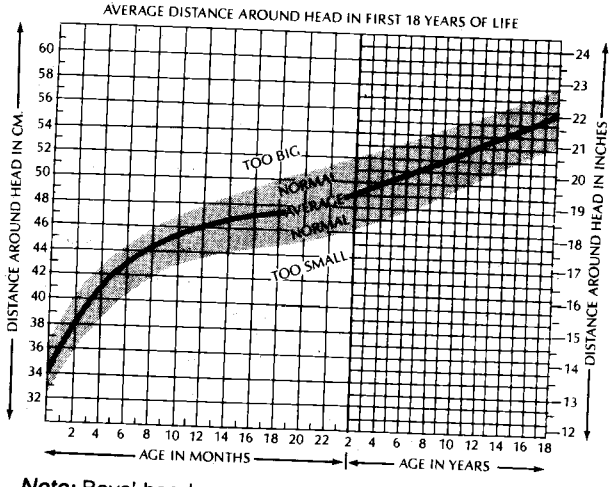
Measure around the widest part of the head.

If the dot is below the shaded area the head is smaller than normal. The child may be **microcephalic** (small-brained, see p. 337).



If the dot falls above the shaded area, the head is bigger than normal. The child may have **hydrocephalus** (see p. 195).

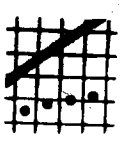




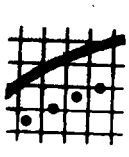
Note: Boys' heads average from 1/2 to 1 cm. larger than girls' heads. Also head size may vary somewhat with different races. If possible get local charts.

Use the chart for a continuing record. Every month put a new dot on the chart. * If the difference from normal increases, the problem is more likely to be serious. For example,

Brain not growing much. Probably microcephalic.



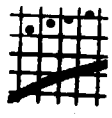
Brain growing well. Probably not serious.



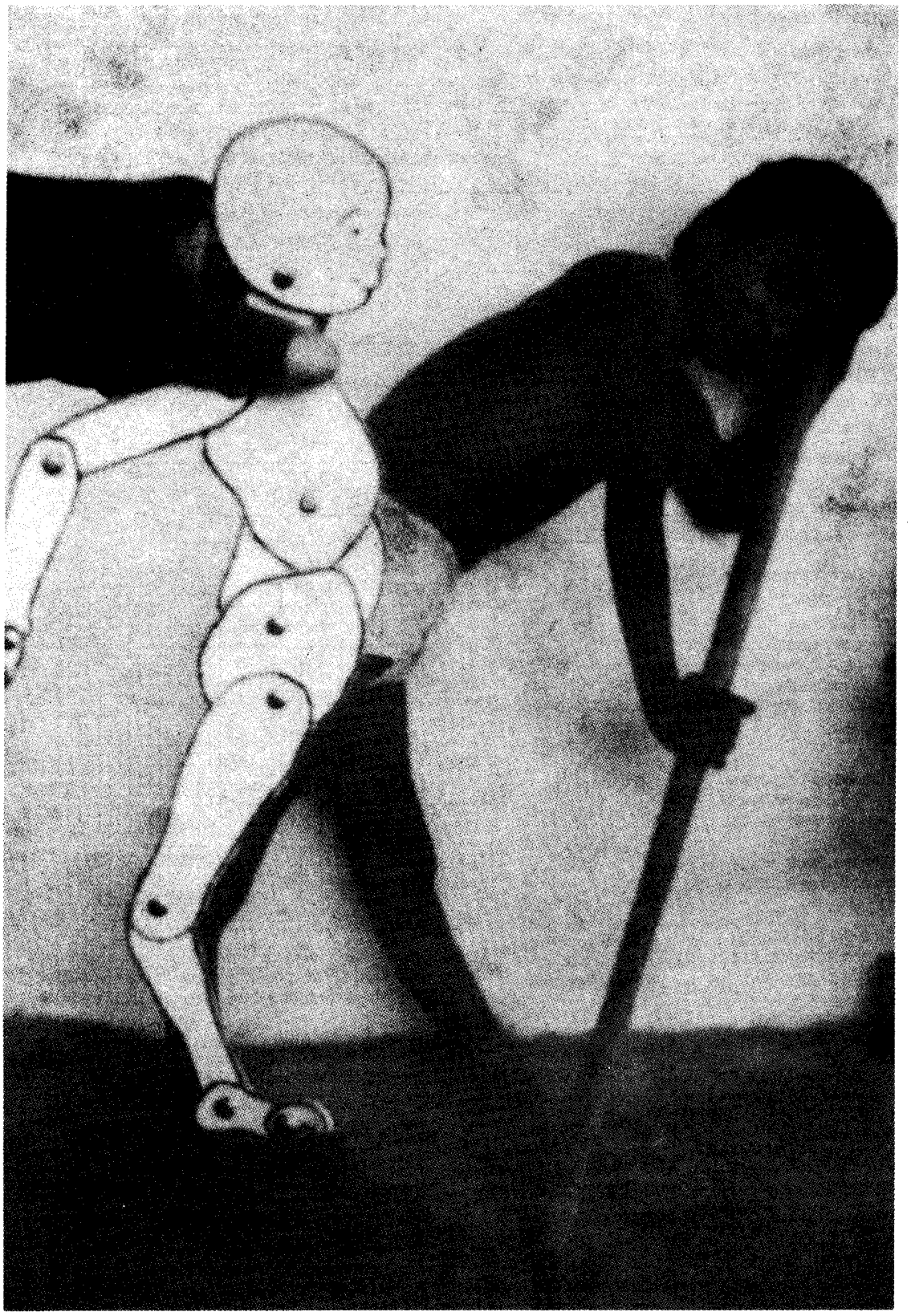
Head too big; growing fast. Hydrocephalus or tumor. Getting worse.



Large head. Probably not a problem



*Filling out this chart every month is especially important for children with spina bifida or suspected hydrocephalus (see p. 195). If you do not know how to use the chart, ask a local school teacher.



CHAPTER 5

Simple Ways to Measure and Record a Child's Progress

It is important to keep records of each child's progress. Careful records help workers and parents to **follow the change in the individual child, and to evaluate the effectiveness of advice, therapy, and aids.**

We need a clear view of the progress of the **whole child in all areas** – physical, mental, and social. The Child Development Chart on p. 360 and 361 will help us to do this for younger children. For children over 5, at the end of this chapter there is a simple chart (RECORD SHEET 5) for evaluating a child's increasing ability to do things.

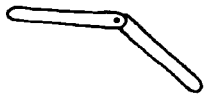
When the parents and child themselves regularly measure and record a child's progress, they become more aware of gradual improvements. This encourages them to continue with important exercises, aids, and activities.

Unfortunately, the standard way of recording physical deformities and *contractures* requires knowledge of angles, degrees, and symbols that many people do not understand. **For evaluation to become a family tool, we need a way to measure, record, and interpret information that is as simple, clear, and enjoyable as possible.** Here are some ideas.

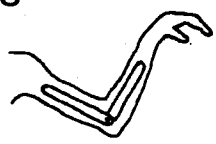
MEASURING JOINT POSITIONS AND CONTRACTURES

You can make a simple measuring tool using 2 flat pieces of wood, plastic, or cardboard. (Tongue depressors work well.)

1. Rivet the pieces together on one end.



2. Line them up exactly with the joint.



3. Trace the angle on paper.



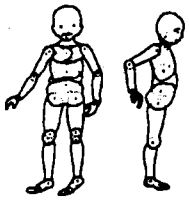
4. Do this again every 1 or 2 weeks to see if the joint is straightening with exercise.



Other simple methods for recording joint positions are on p. 89.

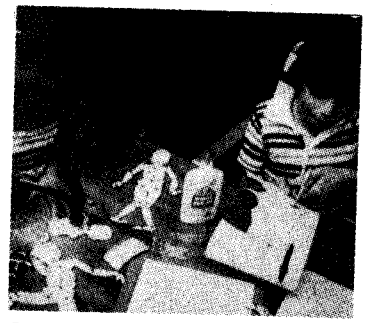
The 'flexikin' – an aid to measure and encourage progress

Flexikins are cardboard dolls with joints. Disabled and non-disabled children can make and play with them. They are **so easy to use that even parents who cannot read can measure and record their children's contractures.** Because the periodic measurements are recorded as a line of pictures, anyone can see the child's progress at a glance.



Flexikins–front and side view models

We have found that when families follow their child's progress using flexikins, both the child and parents are more likely to keep doing stretching exercises. As a result, many contractures can be partly or completely straightened in the home, and there is less need for casting and surgery.



Children making and playing with flexikins. In the PROJIMO village rehabilitation center, all the flexikins used are made by disabled children and the local school children.

Examples of how flexikins are used:

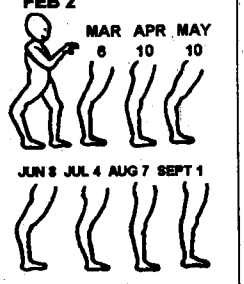


Village rehabilitation workers have just made a brace for a child with polio whose leg bends back severely. They want to know if the leg will gradually get better (bend back less). So they ask the mother to measure it every month.

The mother places the flexikin's leg in the same position as her son's leg, bent back as far as it goes. She then traces it onto a large sheet of paper.

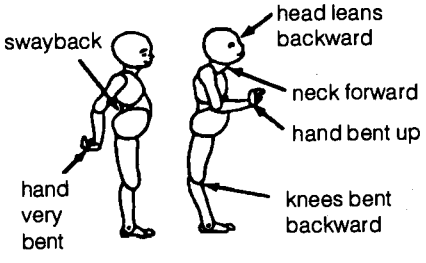


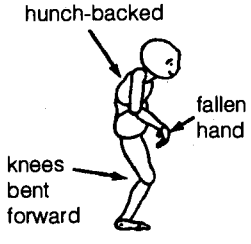




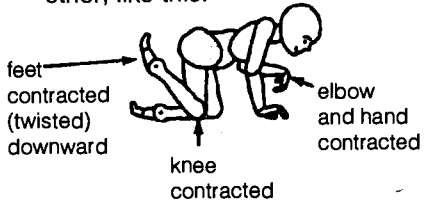
Each month she does the same and records the date. (In April her son did not use the brace for 2 weeks and she saw the knee was getting worse. This convinced both mother and boy of the importance of using the brace.)

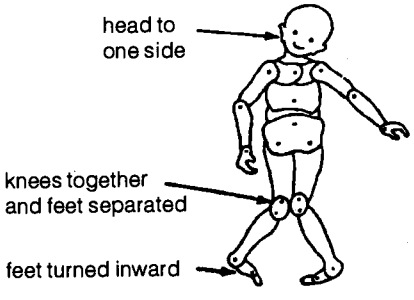
The flexikins can be used to record a wide variety of positions, deformities, contractures, and limitations in range of motion, mainly of the arms and legs but also of the neck, back, hips, and body:

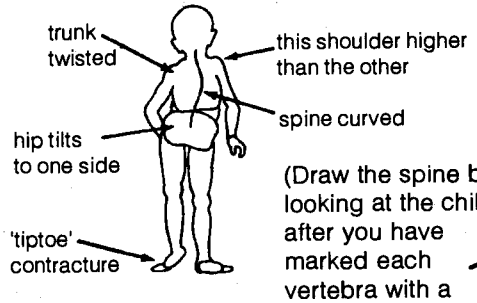




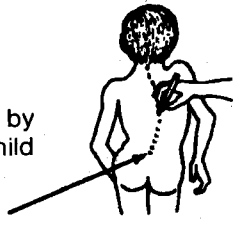
You can draw both arms and legs. First one and then the other, like this:







(Draw the spine by looking at the child after you have marked each vertebra with a marker.)



In addition to using the small flexikins for record keeping, you can make large flexikins for group teaching. Or use them to keep body proportions correct when making drawings for instruction sheets.

Note: For recording contractures, we have found the side-view flexikin more useful than the front-view one. The side-view flexikin is also easier to make. It is probably the only one you will need for evaluating a child's progress.

How to make the flexikins

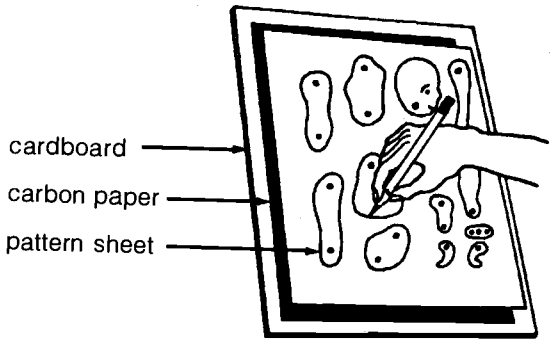
1. Trace the patterns of different pieces (p. 49 and 50) onto very thick paper or thin, firm cardboard. Or use old X-ray film.

You can do this using *carbon paper.* (Make your own carbon paper by completely blackening a sheet of paper with a soft-leaded pencil.)

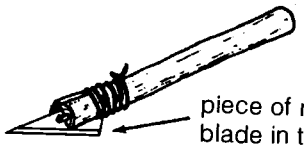
Or you can glue a copy of the pattern sheet directly to the cardboard.



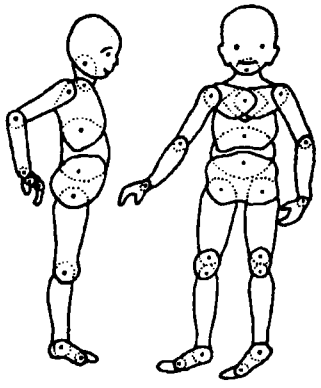
(If your program plans to make many flexikins, or have children make them, we suggest you have the patterns printed or mimeographed directly on sheets of thin, firm cardboard.)

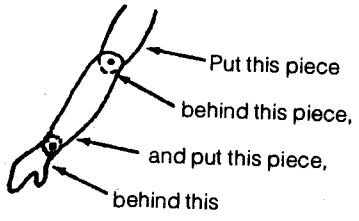


2. Cut out the pieces with strong scissors, shears, or a piece of razor blade.



3. Place the pieces together as shown in the drawings. Make sure the pieces that overlap with dotted lines go behind those with complete lines.



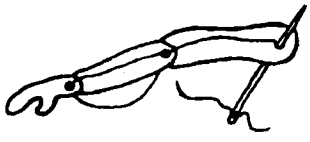


4. Fasten the pieces together at the black dots with rivets, pins or thread.

Use the smallest rivets you can find.



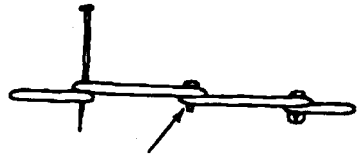
Or string the joints together with thread or yarn (this does not work as well).



Or use thin wire or string and tie knots.



Or use sewing pins;



cut here and put a drop of very strong glue (like epoxy) here.

Rivets usually work best. First punch a hole through each black dot. Put the rivets through and **hammer them just enough so that the cardboard joints are tight enough to hold their positions but can be moved without tearing.**

You can copy this sheet, or one like it, and give it to parents together with a flexikin. Be sure that you also **show them** how to use it and then **watch them use it.**

INSTRUCTIONS FOR USING THE FLEXIKIN

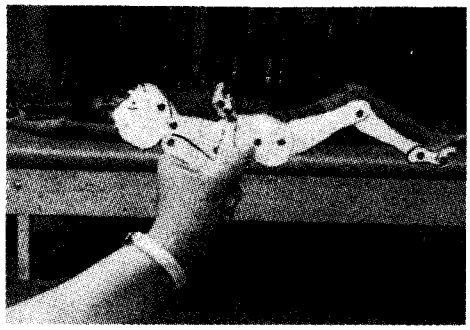
We have given you a 'flexikin' so that you can measure and see the progress that your child is making with his exercises or aids.

We suggest you take a new measurement every _____
Do it like this:

1. Have your child take the position you want to measure (for example, straighten his knee as much as he can) .

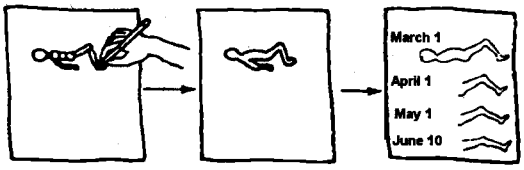


2. Put the flexikin in exactly the position the child is in. To do this **hold the flexikin at a distance between your eye and the child so that it appears the same size as the child.** This will let you line it up exactly.





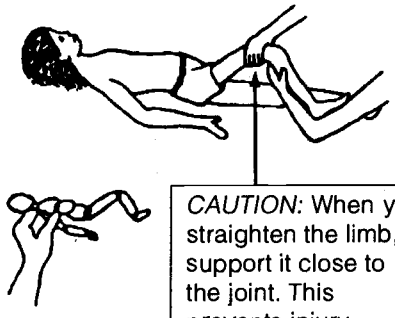
3. Without moving the position of the flexikin, trace it onto a large piece of paper. The first time trace the whole body. Each time measure the child in the same posture.



This example shows how exercises have helped straighten a contracted knee.

For later recordings, you only need to trace the part or parts you are measuring. Each time you record a measurement, write the date.

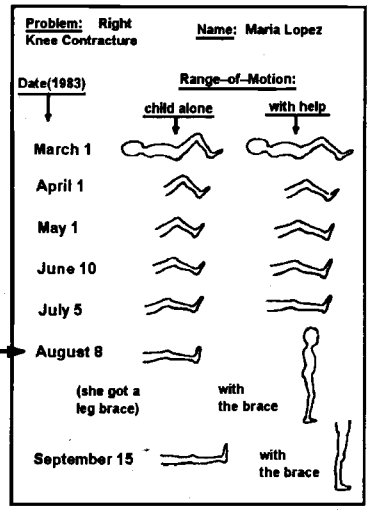
In certain cases you may want to measure how far the child can straighten an arm or leg by herself, and how far you are able to straighten it for her (little by little without forcing).



CAUTION: When you straighten the limb, support it close to the joint. This prevents injury.

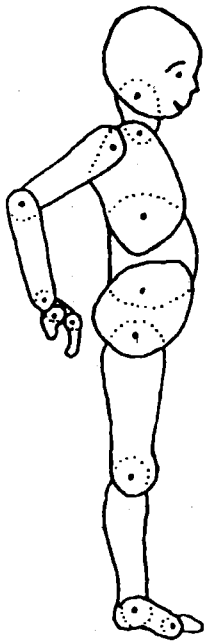
Make 2 columns. In one, record how far the child can move it by herself. In the other column record how far she can move it with help.

Here you see the progress of a leg until it became straight and a brace could be made for it.



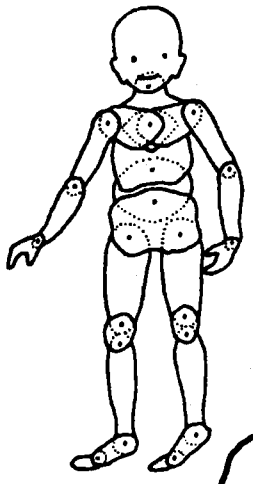
SIDE-VIEW FLEXIKIN

Patterns of pieces for making it



FRONT-VIEW FLEXIKIN

Patterns of pieces for making it

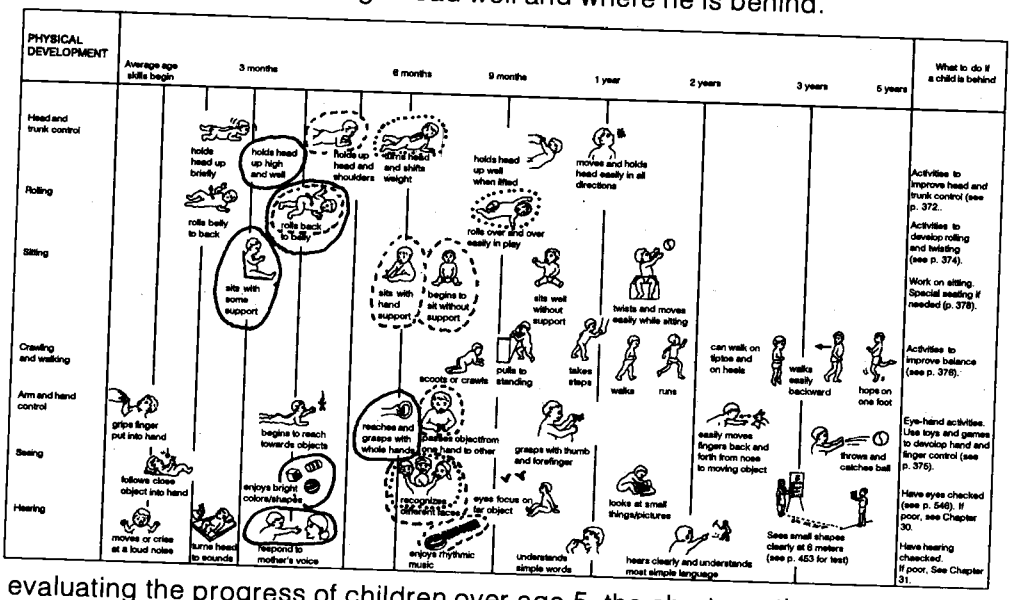


EVALUATING THE PROGRESS OF THE WHOLE CHILD

A simple way for rehabilitation workers and parents to evaluate how a child is progressing as a whole is to keep a record of her ability to do different things. Each month, or during each visit to the community rehabilitation center, the child's different abilities are reviewed, tested, or observed. Any changes are recorded.

For children under 5 years old, one way of evaluating a child's development is to use the RECORD SHEET 6 (p. 360). This chart shows the developmental levels ('milestones') for different skills and activities. The first time the child is evaluated, circle the drawing that shows what the child can do in each area.

Each time the child is evaluated, on the same sheet, again circle the appropriate drawing, **but use a different color** (or a dotted, dashed, or zigzag line). This way, you can see where the child is moving ahead well and where he is behind.



For evaluating the progress of children over age 5, the charts on the next page may help. Two different approaches are used. Chart A is more **objective** (requires less personal judgment or opinion) but does not allow for small improvements. Chart B is more **subjective** (is based more on personal judgments). It considers **quality** of improvement, not just quantity. You can try both and see which you think gives truer, more useful results.

To use Chart A: For each skill, circle, whether the child can do it "without help," "with a little help," or "with lots of help." Add all the numbers you circle. Compare the scores of the first and second visit. For example:

	First visit			Second visit		
	without help	little help	lots of help	without help	little help	lots of help
How does the child eat?	4	(2)	0	(4)	2	0
How does the child drink?	4	(2)	0	4	(2)	0

Here we see the child has improved his eating skills but not his drinking skills.

To use Chart B: In each area, on the second visit, circle whether the child is doing a lot better, or the same. Add it all up. The higher the score, the more the child has improved.

NOTE: We question whether the use of numbers may not be misleading. But we think the questions themselves may be a useful guideline. None of these evaluation forms will show all areas of change or improvement. They are not substitutes for **detailed notes, drawings,** and a **good memory!**

EVALUATION OF PROGRESS - CHILD OVER AGE 5

RECORD SHEET 5

Name_____ Age _____ Disability _____

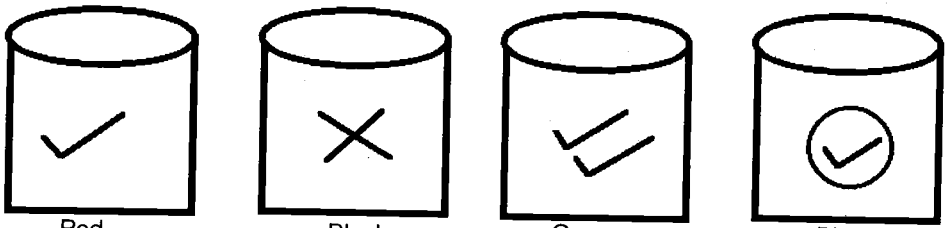
CHART A
Daily activities

	First visit (date_____)			Second visit (date_____)		
	without help	little help	lots of help	without help	little help	lots of help
Feeding						
1. How does the child eat?	4	2	0	4	2	0
2. How does the child drink?	4	2	0	4	2	0
Dressing and washing						
3. Does child wash face and body?	4	2	0	4	2	0
4. Does child dress?	4	2	0	4	2	0
5. Does child put on orthopedic equipment?	4	2	0	4	2	0
Bowel and bladder care and control						
6. Does child stay clean (bowel control)?	4	2	0	4	2	0
7. Does child clean herself after shitting?	4	2	0	4	2	0
8. Does child stay dry during the day?	4	2	0	4	2	0
9. Does child stay dry at night?	4	2	0	4	2	0
Mobility/transfers						
10. Does child move from chair to bed and back?	4	2	0	4	2	0
11. Does child move from floor to bed and back?	4	2	0	4	2	0
Movement						
12. Walks on flat surface?	4	2	0	4	2	0
13. Walks on uneven surface?	4	2	0	4	2	0
14. Climbs up and down stairs?	4	2	0	4	2	0
15. Uses a wheelboard or wheelchair?	4	2	0	4	2	0
16. Does child crawl?	4	2	0	4	2	0
Social activities/communication						
17. Does child help with housework or farm work?	4	2	0	4	2	0
18. Does child play with other children?	4	2	0	4	2	0
19. Does child go to school?	4	2	0	4	2	0
20. Does child speak?	4	2	0	4	2	0
21. Does child communicate with signs or gestures?	4	2	0	4	2	0
		Total _____			Total _____	

CHART B
Quality of activities

	First visit make notes for comparison here	Second visit much better	a little better	same	worse
Does child move about better?		4	2	0	–4
Does he sit in a better position?		4	2	0	–4
Does he walk better (straighter, with less limp or with less support)?		4	2	0	–4
Does he walk farther, faster, or easier?		4	2	0	–4
Are his joints straighter (less contractures)?		4	2	0	–4
hip?		4	2	0	–4
knee?		4	2	0	–4
ankle?		4	2	0	–4
Can the child do things he could not do before?		4	2	0	–4
feeding?		4	2	0	–4
bathing?		4	2	0	–4
dressing?		4	2	0	–4
toileting?		4	2	0	–4
Does he play with things better?		4	2	0	–4
Does he speak or communicate better?		4	2	0	–4
Does he get along with other children better?		4	2	0	–4
Does he seem happier or more self-confident?		20	8	0	–4
Has he improved or got worse in other ways?		4	2	0	–4
In what ways? _____		4	2	0	–4
_____				Total _____	

For recording a child's progress here is another simple way for parents who cannot read or write. Tins or boxes or any type of containers with lights available in the home may be used for this. Take four of these as shown in the picture. Make a hole in each of the lids so that you can toss a pebble in easily. Wrap them up with plain paper. Make the boxes as done below. If possible use different colours to help identify the different boxes



Red	Black	Green	Blue
Can do without help	Cannot do or refuses to do	Can do very well	Can do with help

You can keep on tossing in pebbles one at a time in the different boxes as the ability of the child changes. Here you have both the signs and the colours to recognise the different stages of your child's development. You can also use these boxes to record the number of times a child gets fits in a month or for recording the regularity of the medicines given for fits. (SEVA-IN-ACTION, Bangalore).

NOTES

CHAPTER 6

Guide for Identifying Disabilities

This chapter has a chart, 7 pages long, to help you find out **what disability a child possibly has**, and **where to look up that disability in this book.**

In the **first column** of the chart, we list the more noticeable signs of different disabilities. Some of these signs are found in more than one disability. So in the **second column** names the disability or disabilities that are most likely to have these signs. And the **fourth column** gives the page numbers where you should look in this book. (Where it says ***WTND*** and then a number, this refers to the page in *Where There Is No Doctor).*

If you do not find the sign you are looking for in the first column, look for another sign. Or check the signs in the second column.

The chart will help you find out which disabilities a child might have. It is wise to look up each possibility. **The first page of each chapter on a disability describes the signs in more detail.**

> ***IMPORTANT:*** Some disabilities can easily be confused. Others are not included in this book. When you are not sure, try to get help from someone with more experience. At times, special tests or X-rays may be needed to be sure what the problem is.

Fortunately, **it is not always necessary to know exactly what disability a child has.** For example, if a child has developed weakness in his legs and you are not sure of the cause, you can still do a lot to help him. Read the chapters on disabilities that cause child, you might find useful information in the chapters on polio, *contractures*, exercises, braces, walking aids or wheelchairs, and many others.

Sometimes it is important to identify the specific disability. Some disabilities require specific medicines or foods – for example, night blindness, rickets, or cretinism. Others urgently need surgery – for example, spina bifida or cleft lip and palate. Others require special ways of doing ***therapy*** or exercises – for example, cerebral palsy. And others need specific precautions to avoid additional problems – for example, spinal cord injury and leprosy. For this reason, it helps to learn as much about the disability as you can. Whenever possible, seek information and advice from more experienced persons. (However, even experts are not always right. Do not follow anyone's advice without understanding the reasons for doing something, and considering *if* and *why* the advice applies to the individual child.)

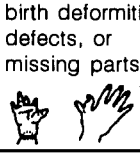
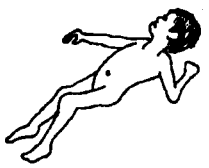
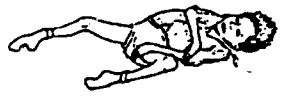


In addition to this chart, 2 other guides for identifying disabilities are in this book:

GUIDE FOR IDENTIFYING CAUSES OF JOINT PAIN, P. 150.
GUIDE FOR IDENTIFYING AND TREATING DIFFERENT FORMS OF FITS (EPILEPSY), P. 287.

GUIDE FOR IDENTIFYING DISABILITIES

SIGNS PRESENT AT OR SOON AFTER BIRTH.

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE	SEE PAGE
born weak of 'floppy' 	• often a difficult birth • delayed breathing • born blue and limp • or born before 9 months and very small	• cerebral palsy • developmental delay	97 333
slow to begin to lift head or move arms 	• round face • slant eyes • thick tongue 	• Down syndrome (mongolism) • cretinism	339 342
	small head, or small top part of head 	microcephalia (small brain) mental retardation	337
	none of above	developmental delay for other reasons	357
does not suck suck well or choke on milk or food 	• pushes milk back out with tongue • or will not suck	cerebral palsy	97
	• cannot suck well • chokes or milk comes out nose	• check for cleft palate  • possibly severe retardation	140 333
one or both feet turned in or back 	• no other signs	• club foot	128
	• hands weak, stiff or clubbed • some joints stiff, in bent or straight positions 	arthrogryposis	142
	dark lump on back	spina bifida	189
'bag' or dark lump on back 	• clubbed feet • or feet bend up too far  • or feet lack movement and feeling	spina bifida (sometimes no 'bag' is seen, but foot signs may be present)	189
head too big; keeps growing 	may develop: • eyes like 'setting sun'  • increasing mental and/or physical disability • blindness	hydrocephalus (water on the brain)	195
		At birth, this is usually a sign of spina bifida	189
		in an older child, possibly tapeworm in brain, or a brain tumor	*WTND* 344
upper lip and/or roof of mouth incomplete 	• difficulty feeding • later, speech difficulties 	cleft lip (hare lip) and cleft palate	140
birth deformities, defects, or missing parts 	(may or may not be associated with other problems)	See • birth defects • amputations • Down syndrome • developmental delay	 139 269 339 355
abnormal stiffness or position 	• from birth • some muscles weak • some joints stiff • head control and mind normal	arthrogryposis 	142
	• Muscles tighten more in certain positions. • may grip thumb tightly 	spastic cerebral palsy ***Note:*** muscle tightness (spasticity) usually does not appear until weeks or months after birth.	99

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE	SEE PAGE
one arm weak or in strange position 	does not move the arm much holds it like this 	Erb's palsy (weakness from damage to nerves in shoulder during birth)	147
	leg on same side often affected	hemiplegic (one-sided) cerebral palsy	100
dislocated hip at birth leg held differently, shorter; flap covers part of vulva 	On opening legs like this, leg 'pops' into place or does not open as far  	dislocated hip from birth (often both hips) may be present with : • spina bifida • Down syndrome • arthrogryposis Also see p. 176	175 189 339 142
slow to respond to sound or to look at things 	(may be due to one or a combination of problems)	Check for signs of : • developmental delay • cerebral palsy • blindness • deafness	 358 97 291 307

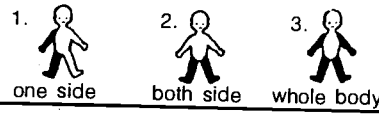
SIGNS IN CHILDREN

slower than other children to do things (roll, sit, use hands, show interest, walk, talk) 	slow in most or all areas:	Developmental delay, check for signs of:	355
	• round face • slant eyes • single deep crease in hand 	Down syndrome (mongolism)	339
	• movements and response slow • skin dry and cool • hair often low on forehead • puffy eyelids 	cretinism	342
	has continuous strange movements or positions, and/or stiffness	cerebral palsy also check for: • blindness • deafness • malnutrition	97 291 307 392
does not respond to sounds, does not begin to speak by age 3 	may respond to some sounds but not others Check for ear infection (pus).	Check for: • deafness • severe developmental delay(with or without deafness) • severe cerebral palsy	 307 345 97
does not turn head to look at things, or reach for things until they touch her 	Eyes may or may not look normal	• blindness and or • severe mental retardation • severe cerebral palsy	291 333 15 97
Eyelids or eyes make quick, jerky, or strange movements. 	Check for one or a combination of these	• blindness • fits • too much medicine • cerebral palsy • other problems affecting or damaging the brain	291 283 15 97 14

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE	SEE PAGE
All or part of body makes strange, uncontrolled movements. 	• begins suddenly, child may fall or lose consciousness • child is normal (or more normal) between 'fits'	epileptic fits (Pattern varies a lot in different children – or even in the same child)	283
	slow, sudden, or rhythmic movements: fairly continuous (except in sleep); no loss of consciousness 	athetoid cerebral palsy (*Note:* Fits and cerebral palsy may occur in the same child.)	99
Body, or parts of it, stiffens when in certain positions: poor control of some or all movements	• different positions in different children • Body may stiffen backward and legs cross. 	spastic cerebral palsy	99

PARTS OF BODY WEAK OR PARALYZED

floppy or limp weakness in part or all of body no loss of **feeling** in affected parts no **spasticity** (muscles that tighten without control) **normal at birth**	• usually began with a 'bad cold' and fever before age 2  • irregular pattern of parts weakened. Often one or both legs – sometimes arm, shoulder, hand, etc.	polio	63
	• begins little by little and steadily gets worse • about the same on both sides of body • often others in the family also have it 	• muscular dystrophy • muscular atrophy	123 126
		tick paralysis 	not in book
		Guillain–Barrē paralysis (usually temporary)	66
	• Paralysis starts in legs and moves up; may affect whole body. • or, pattern of paralysis variable	paralysis from pesticides, chemicals, foods (lathyrism)	15
	lump on back (see p. 61.)	tuberculosis of spine	185
floppy or limp weakness usually **some** loss of **feeling**	• one or both hands or feet  • develops slowly in older child. Gets worse and worse.	leprosy	253
	• born with bag on back (look for scar.)  • feet weak, often without feeling	spina bifida 	189
	• usually from back or neck injury • weakness, loss of feeling below level of injury • may or may not have muscle spasms • loss of bladder and bowel control	spinal cord injury  paraplegia (lower body) quadriplegia (upper and lower body) 	203
	injury to nerves going to one part of body	hand weakness sometimes caused by using crutches wrongly	481

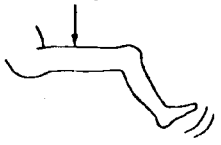
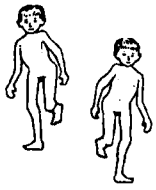
IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE	SEE PAGE
weakness usually with stiffness or spasticity of muscles no loss of feeling	usually affects body in one of these patterns  1. one side 2. both side 3. whole body	• 1: cerebral palsy (or stroke, usually older persons) • 2 and 3: cerebral palsy • occasional other causes	97
	Muscles tighten and resist movement because of joint pain.	JOINT PAIN (many causes – see below)	150

JOINT PAIN

one or more painful joints	• begins with or without fever • gradually gets worse, but there are better and worse periods 	juvenile arthritis	155
		other causes of joint pain See chart on joint pain.	150

WALKS WITH DIFFICULTY OR LIMPS

dips to one side with each step 	one leg often weaker and shorter	Check for: • polio • cerebral palsy • dislocated hip	63 97 175
	• usually begins age 4 to 8 • may complain of knee pain	damaged hip joint	177
walks with knees pressed together 	• muscle spasm and tightness • upper body little affected	spastic diplegic or paraplegic cerebral palsy	97
stand and walks with knees together and feet apart  no other problems	 feet less than 3" apart at age 3	normal from ages 2 to 12	127
	 feet more than 3" apart age 3	knock – kneed	128
walks awkwardly with one foot tiptoe 	muscle spasms and poor control on that side. Hand on that side often affected	hemiplegic cerebral palsy	100
		(stroke in older persons)	not in book
walks awkwardly with knees bent and legs usually separated 	• jerky steps, poor balance sudden, uncontrolled movements that may cause falling	athetoid cerebral palsy	99
	• slow 'drunken' way of walking • learns to walk late and falls often	• poor balance (ataxia) – often with cerebral palsy • Down syndrome (mongolism) • cretinism	100 339 342
walks with both feet tiptoe 	• weakness, especially in legs and feet • gradually gets worse and worse	muscular dystrophy	123
	legs and feet stiffen (spasticity of muscle)	spastic cerebral palsy	99

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE	SEE PAGE
walks with hand(s) pushing thigh(s) or with knee(s) bent back 	weak thigh muscle  lifting leg	• polio • muscular dystrophy • arthritis (joint pain) • other causes of muscle weakness	63 123 155 126
Foot hangs down weakly (foot drop.) 	Child lifts foot high with each step so that it will not drag. 	• polio • spina bifida • muscular dystrophy • muscular atrophy • never or muscle injury • other cause of weakness	63 189 123 126 37 159
dips from side to side with each step 	due to muscle weakness at side of hips, or double dislocated hips, or both.	• polio • cerebral palsy • spina bifida • Down syndrome • muscular dystrophy • child who stays small • arthrogryposis • dislocated hips (may occur with any of the above)	63 97 189 339 123 146 142 175
walks with one (or both) hip, knee, or ankle that stays bent 	joints ***cannot*** be slowly straightened when child relaxes (see page 89).	• contractures (shortened muscles) • joined or fused joints may be secondary to: • polio • joint infection • other causes	87 90 63 151 277
	Joints ***can*** gradually be straightened when child relaxes.	spasticity, often cerebral palsy	99
Knees wide apart when feet together (bow legs). Waddles or dips from side to side (if he walks). 	under 18 months old	often normal	127
	Any combination of these : • Joints look big or thick. • Child is short for age. • Bones weak, bent, or break easily. • Arms and legs may seem too short for body, or 'out of proportion'. • Belly and butt stick out a lot. 	Consider: • rickets (lack of vitamin D and sunlight) • brittle bone disease • children who stay very short (dwarfism) • cretinism • Down syndrome • dislocated hips	 145 145 146 342 339 175
flat feet 	no pain or other problems	normal in many children	127
	• Pain may occur in arch of foot. • Deformity may get worse.	may be problems in: • cerebral palsy • polio • spina bifida • Down syndrome	 97 63 189 339

BACK CURVES AND DEFORMITIES

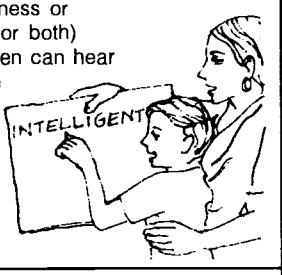
sideways curve of backbone 	When child bends over, look for a lump on one side. 	'scoliosis'— may occur alone or as complication of: • polio • cerebral palsy • muscular dystrophy • spina bifida • other physical disability	 63 97 123 189 182

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE	SEE PAGE
swa 	• belly often sticks out • may be due to contractures here, or weak stomach muscles	'lordosis' – may occur in: • polio • spina bifida • cerebral palsy • muscular dystrophy • Down syndrome • cretinism • child who stays small • many other disabilities	 63 189 97 123 339 342 146 181
rounded back 		'kyphosis' – often occurs with: • arthritis • spinal cord injury • severe polio • brittle bone disease	 155 203 63 145
hard, sharp b of of bump in backbone 	• starts slowly and without pain • often family history of tuberculosis • may lead to paralysis of lower body	tuberculosis of the spine	185
dark soft lump over backbone 	• present at birth • sometimes only a soft or slightly swollen are over spine • weakness and loss of feeling in feet or lower body	spina bifida ('sack on the back')	189

OTHER DEFORMITIES

missing body parts	born that way 	born with missing or incomplete parts	141
	accidental or surgical loss of limbs (amputation) 	amputations	269
	gradual loss of fingers, toes, hands, or feet, often in persons who lack feeling 	• osteomyelitis (bone infections) Sometimes seen with: • leprosy (hands or feet) • spinal bifida (feet only)	179 253 189
hand problem (For hand problems from birth, see p. 375)	• floppy paralysis (no spasticity)  • without care may lead to contractures so that fingers cannot be opened	may occur with: • polio • muscular dystrophy • muscular atrophy • spinal cord injury (at neck level) • leprosy • damage to nerves or cords of arms All may lead to contractures.	 63 123 126 205 253 147
	• uncontrolled muscle tightness (spasticity) • strange movements • or hand in tight fist 	spastic cerebral palsy may lead to contractures	99
	burns scars and deformities 	burn	231
clubbing or bending of feet (For club feet from birth, see p. 128)	may begin as floppy weakness and become stiff from contractures, if not prevented 	may occur with many physical disabilities, including • polio • cerebral palsy • spina bifida • muscular dystrophy • arthritis • spinal cord injury	 63 97 189 123 159 203

DISABILITIES THAT OFTEN OCCUR WITH OR ARE SECONDARY TO OTHER DISABILITIES

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE	SEE PAGE
Developmental delay: child slow to learn to use her body or develop basic skills 	caused by slow or incomplete brain function or by severe physical disability, or both	often seen in: • mental retardation • cerebral palsy • severely or multiply	 333 97 345
	caused by overprotection: treating children like babies when they could do more for themselves	some delay can occur with almost any disability	355
Contractures joints that no longer straighten because muscles have shortened  joints will not straighten	• usually due to muscle weakness or spasticity • Often, muscles that pull a joint one way are much weaker than those the pull it the other way (muscle imbalance).	often secondary to: • polio • cerebral palsy • spina bifida • arthritis • muscular dystrophy • Erb's palsy • amputations • leprosy	 63 97 189 155 123 147 269 253
	sometimes due to scarring from burns or injuries	burns	277
Behavior problems 	may come from: • brain damage • difficulty understanding things • Over protection • difficult home situation (Some children with epilepsy from brain damage may pull out hair, bite themselves, etc.)	behavior problems common with: • mental retardation • fits (epilepsy) • cerebral palsy and for emotional reasons,with: • spinal cord injury • muscular dystrophy • deafness • learning disability	 333 283 97 203 123 307 449
Slow to learn certain things only; otherwise intelligent.	• often over-active or nervous • sometimes behavior problems	learning disability	449
Speech and communication problems	• often, but not always, due to deafness or retardation (or both) • Some children can hear well and are  but still cannot speak.	may occur with • deafness • developmental delay • cerebral palsy • Down syndrome • cretinism • children who stay small • brittle bone disease • cleft lip and palate Deafness may occur together with these and other disabilities)	 307 355 97 339 342 146 145 140
other problems that sometimes occur ***secondary*** to other disabilities (Some of these we have already include in this chart.)	**Main disability** • cerebral palsy • many disabilities with paralysis • persons who have lost feeling leprosy, spinal cord injury, spina bifida	**Common secondary disabilities** • blindness • deafness • fits • spinal curve • pressure sores • osteomyelitis (bone infection) • loss of urine and bowel control	 291 307 283 181 229 179 239

CHAPTER 7

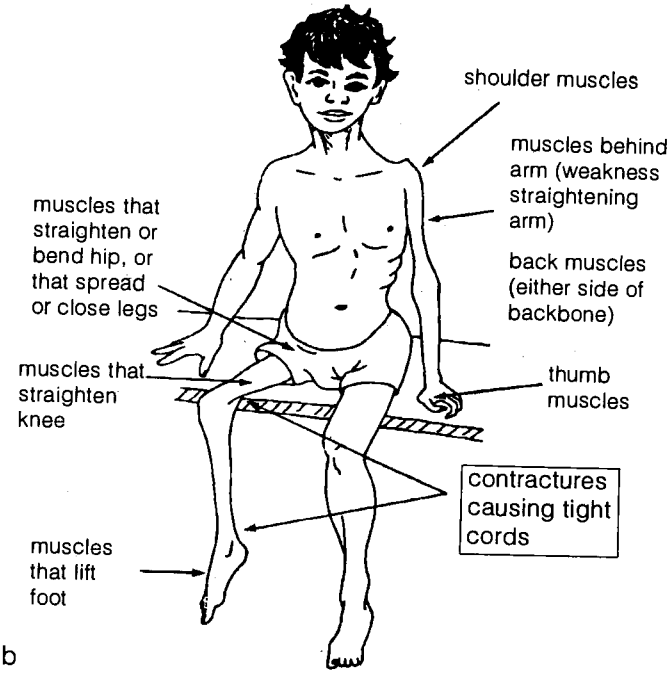
Polio

Infantile Paralysis

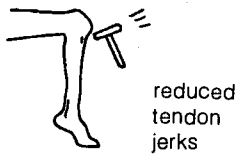
HOW TO RECOGNIZE PARALYSIS CAUSED BY POLIO

- ***Paralysis*** (muscle weakness) usually begins when the child is small, often during an illness like a bad cold with fever and sometimes diarrhoea.
- Paralysis may affect any ***muscles*** of the body, but is most common in the legs. Muscles most often affected are shown in the drawing.
- Paralysis is of the **'floppy'** type (not stiff). Some muscles may be only partly weakened, others limp or floppy.
- In time the affected limb may not be able to straighten all the way, due to shortening, or ***'contractures'***, of certain muscles.
- The muscles and bones of the affected limb become thinner than the other limb. The affected limb does not grow as fast, and so is shorter.

MUSCLES COMMONLY WEAKENED BY POLIO



- Unaffected arms or legs often become extra strong to make up for parts that are weak.
- **Intelligence** and the mind are not affected.
- **Feeling** is not affected.
- 'Knee jerks' and other ***tendon*** reflexes in the affected limb are reduced or absent. (In cerebral palsy, 'knee jerks' often jump more than normal. See p. 98.) Also, the paralysis of polio is 'floppy'; limbs affected by cerebral palsy often are tense and resist when straightened or bent (see p. 115).



reduced tendon jerks

- The paralysis does not get worse with time. However, secondary problems like contractures, curve of the backbone and ***dislocations*** may occur.

Of children who become paralyzed by polio:

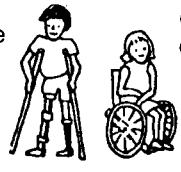
30% recover completely in the first weeks or months.



30% have mild paralysis.



30% have moderate or severe paralysis.



10 % die (often because of difficulty breathing or swallowing.)



BASIC QUESTIONS AND ANSWERS ABOUT POLIO

How common is it? In India polio is the single most common cause of physical *disability* amongst children. The prevalence of polio varies greatly amongst different states and districts in the country. For example in 1989 the district of Dibrugarh in Assam had less than one child (below the age of five) per thousand children. Where *vaccination* programs are effective polio has been greatly reduced.



Paralysis in one leg

What causes it? A *virus (infection).* The infection attacks parts of the ***spinal cord***, where it damages only the ***nerve cells*** that control movement. In areas with poor hygiene and lack of latrines, the **polio** infection spreads when the stool of a sick child reaches the mouth of a healthy child. The virus can **contaminate** drinking water or food through flies or dirty hands and attack another child. Where sanitation is better, polio spreads possibly through coughing and sneezing.



severe paralysis

Do all children who become infected with the polio virus become paralyzed? No, only a small percentage become paralyzed. Most only get what looks like a bad cold, with fever. However, if a child with a 'cold' caused by the polio virus is given **an injection of any medication,** the irritation caused by the injection **can bring on paralysis.** (See warning on p. 20.)

Is the paralysis contagious? No, not after 2 weeks from when a child first gets sick with polio. In fact, most polio is spread through the **stool** of non – paralyzed children who have 'only a cold' caused by the polio virus.

At what age do children get polio ? The largest number of children get polio between the ages of 7 to 24 months. About half the reported cases of polio are less than 18 months. This happens mainly in areas with poor sanitation. Although, the risk of polio declines with age, children are more vulnerable to attacks of polio upto the age of 5.

Who does it more often affect ? Boys a little more than girls. Unvaccinated children much more often than vaccinated children. Children living in areas where immunization coverages are low more often than children living in areas where coverage levels are high.

Children in urban slum areas are more often affected than those in middle class or rich residential colonies in the cities. These areas often have poor sanitation with no proper facilities for toileting and lack of safe drinking water. They may be congested with many people living in small unventilated rooms. People from these areas may be shifting constantly in search of work and money. This often leads to inadequate and incomplete vaccinations. Children in rural and urban areas are often given injections by various health workers, for treating fevers. This is considered 'normal' treatment. If however the fever happens to be because of infection due to polio virus, the injection can bring on an attack of paralytic poliomyelitis. In a survey conducted in nine villages of District Sonepat, Haryana, in as many as 68 per cent of the children paralysis was brought on by an injection. (Varghese M. Mohan D. Quadeer I).

During epidemic, outbreaks of water borne diseases like cholera and typhoid, the risk of poliomyelitis also goes up as a result of contamination of drinking water with stool. Vaccinations in the form of injections should not be given during this period for fear of triggering of an attack of paralytic poliomyelitis by the injection.

How does the paralysis begin? It begins after signs of a cold and fever, sometimes with diarrhoea or vomiting. After a few days the neck becomes stiff and painful and parts of the body become limp. Parents may notice the weakness right away, or only after the child recovers from the acute illness

Once a child is paralyzed, what changes or improvements can be expected?. Once the child is paralyzed the paralysis will not go away, nor will it get worse. In the initial acute stage of the disease, the child may not be able to move his limbs because of the pain and paralysis. He may seem more paralyzed than he actually is. Once the pain goes, and as the partially damaged muscles recover, there will be improvement in function. This process can go on upto 7 months. Any paralysis left after 7 months is usually permanent. However, secondary problems of deformities may develop – specially if precautions are not taken to prevent them.

Surely some children do get cured after traditional treatment and massages !
No! so far there is no drug, Allopathic, Ayurvedic or Homeopathic which can cure paralytic polio. Since 30 percent of the children getting paralysis may recover to a large extent on their own, people may conclude that this is due to some drug, potion or massage, whereas it would have happened in any case. Once the initial acute stage of the illness is over, massaging the affected limbs can help keep the limbs toned. Passive exercises can also be built into the massage routine. Passive exercises are built into the massages routine.

Once you notice paralysis when should the child be taken to the hospital?
Consult a health worker or doctor as soon you notice any paralysis in the child. But if the child is developing paralysis of the arms and the hands then probably her paralysis is spreading. This could endanger her breathing muscles and the child may soon have difficulty in breathing. ***This is an emergency.*** Take the child immediately to a well equipped hospital.

Also, if the child is unduly sleepy she should be taken to the hospital.

What are the child's chances of leading a happy, productive life? Usually very good– provided the child is encouraged to do things for himself, to get the most out of school, and to learn useful skills within his physical limitations (see p. 601).

Can persons with polio marry and have normal children? Yes, polio is not inherited (familial) and does not affect ability to have children.

SECONDARY PROBLEMS TO LOOK FOR WITH POLIO

(By ***secondary*** problems, we mean problems that do not come from the original disease or disability, but appear later, as complications.)

CONTRACTURES OF JOINTS

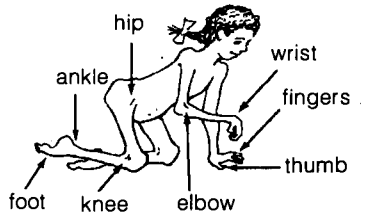
A contracture is a shortening of muscles and tendons (cords) so that the full range of limb movements is prevented.

Unless preventive steps are taken, joint contractures will form in many paralyzed children. Once formed often they must be corrected before braces can be fitted and walking is possible. Correction of advanced contractures, whether through exercises, casts, or surgery (or a combination), is costly, takes time and causes discomfort. Therefore **early prevention of contractures is very important.**

A full discussion of contractures, their causes, prevention, and treatment is in the next chapter (Chapter 8). Methods and aids for correcting contractures are described in Chapter 60.

TYPICAL CONTRACTURES IN POLIO

A child with paralysis who crawls around like this and never straightens her legs will gradually develop contractures so that her hips, knees, and ankles can no longer be straightened.



TYPICAL DEFORMITIES OF ANKLE AND FOOT



bending down at ankle (tiptoe contracture)

bending down at mid – foot

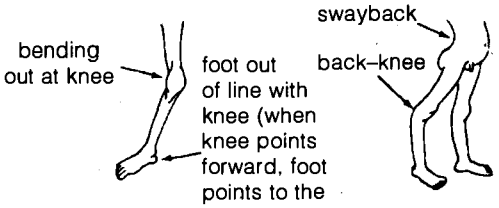
bending out at ankle

bending in at ankle

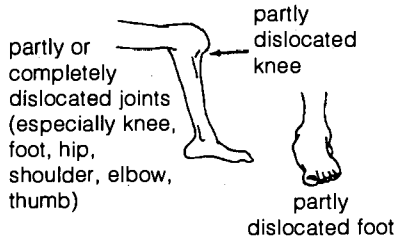
OTHER COMMON DEFORMITIES

Weight bearing (supporting the body's weight) on weak joints can cause deformities.

OVER STRETCHED JOINTS



DISLOCATIONS



WARNING :

Dislocations like these are sometimes caused by stretching contractures incorrectly. (See p. 30.)

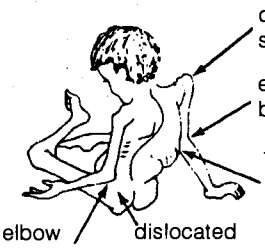
SPINAL CURVE

Minor curve of spine can be caused by tilted hips, as a result of a short leg.



More serious curve of the *spine* is caused by muscle weakness of the back or body muscles. The curve can become so severe that it endangers life by leaving too little room for the lungs and heart.

A severely paralyzed child

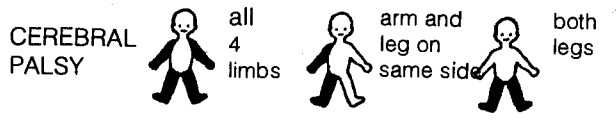


At first, the spinal curve straightens when the child is positioned better. But in time the curve becomes more fixed (will not straighten any more). For information on spinal curves, see chapter 20.

WHAT OTHER DISABILITIES CAN BE CONFUSED WITH POLIO?

- Sometimes **cerebral palsy** can be mistaken for polio–especially cerebral palsy of the 'floppy' type.

However, **cerebral palsy** usually affects the body in typical patterns:



Polio has a more irregular pattern of paralysis:



In cerebral palsy, usually you can find other signs of brain damage: overactive knee jerks and abnormal reflexes (see p. 98), developmental delay, awkward or uncontrolled movement, or at least some muscle tenseness ***(spasticity)***.



- In **muscular dystrophy,** paralysis begins little by little and steadily gets worse (see p. 123)



- **Hip problems** (see p 175) can cause limping, and muscles may become thin and weak. Check hips for pain or dislocations. (***Note:*** Dislocated hip may also occur secondary to polio.)



- **Clubbed foot** is present from birth. (See p.147)



- **'Erb's palsy',** or partial paralysis in one arm and hand, comes from birth injury to the shoulder (see p. 147)



- **Leprosy**. Foot and hand paralysis begins gradually in older child. Often there are skin patches and loss of feeling. (See p.253)

Note: Polio can occur before or after a child has any of these other problems. Check carefully.



- **Tuberculosis of the spine** can cause gradual or suddenly increasing paralysis of the lower body. Look for typical bump on spine (see p.185).



- **Injuries to the spinal cord** (see p.203) or to particular nerves going to the arms or legs. There is usually a history of a severe back or neck injury and loss of feeling in the paralyzed part.

ALWAYS EXAMINE THE BACK IN A CHILD WITH PARALYSIS OF THE LEGS, AND CHECK FOR FEELING.

- **Lathyrism** leads to paralysis of both lower limbs, making the limbs stiff (chapter 34).



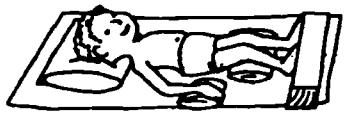
- **Spina bifida** is present from birth. There is reduced feeling in the feet, and often a lump (or scar from surgery) on the back. (see p. 189).
- **A child not moving her limbs** because she has an infection in the joint or bone, or severe lack of vitamin C, or rheumatic fever with joint pain may be mistaken to have paralysis due to polio. Careful examination will reveal the underlying condition.
- **Other causes of paralysis or muscle weakness.** There are many causes of floppy paralysis similar to polio. One of the most common is **'Guillain-Barré'** paralysis. This can result from a virus infection, from poisoning, or from unknown causes. It usually begins without warning in the legs, and may spread within a few days to paralyze the whole body. Sometimes feeling is also reduced. Usually strength slowly returns, partly or completely, in several weeks or months. *Rehabilitation* and prevention of secondary problems are basically the same as for polio.

WHAT CAN BE DONE?

DURING THE ORIGINAL ILLNESS, when the child first becomes paralyzed:

- **No medicines** help, either during the first illness, or later.
- **Rest** is important. **Avoid forceful exercise** because this may increase paralysis. **Avoid injections. Avoid massage.** In some places **tight bandages** are put on children. These should be avoided.
- **Good food** during recovery helps the child become stronger. (But take care that the child does not eat too much and get fat. An overweight child will have more problems with walking and other movements.) For suggestions about good food, see ***Where There is No Doctor***, Chapter 11.
- **Position** the child to be comfortable and to avoid contractures. At first the muscles will be painful, and the child will not want to straighten his joints. Slowly and gently try to straighten his arms and legs so that the child lies in as good a position as possible. (See Chapter 8.)

GOOD POSITION



Arms, hips, and legs as straight as possible. Feet supported.

BAD POSITION

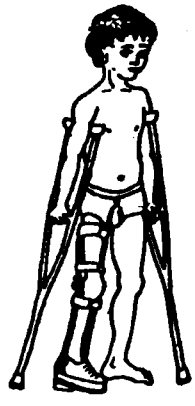


Bent arms, hips, and legs. Feet in tiptoe position.

Note: To reduce pain, you may need to put cushions under the knees, but try to keep the knees as straight as you can.

FOLLOWING THE ORIGINAL ILLNESS:

- Continue with **good food** and **good positions**.
- As soon as the fever drops, start **exercises** to prevent contractures and return strength. **Range – of – motion exercises** are described in Chapter 43. Whenever possible, make exercises fun. **Active games, swimming,** and other **activities to keep limbs moving as much as they can** are important throughout the child's rehabilitation.
- **Crutches, leg braces** (***calipers***), and other aids may help the child to move better and may prevent contractures or deformities.



- In special cases, **surgery** may be needed to correct contractures, or to change the place where strong muscles attach, so that they help do the work of weak ones. When a foot is very floppy or bends to one side, surgery to join certain bones of the foot may help. But because bone surgery stops the growth of the foot, usually it should not be done before age 12 or 13.
- Encourage the child to **use his body and mind** as much as possible, to play actively with other children, to **take care of his daily needs,** to **help with work,** and to **go to school.** As much as possible, **treat him like any other child.**

REHABILITATION OF THE CHILD WITH PARALYSIS

All children paralyzed by polio can be helped by certain basic rehabilitation measures–such as exercise to keep a full range of motion in the affected limbs.

However, **each child will have a different combination and severity of paralyzed muscles, and therefore will have his own special needs.**

For some children, normal exercise and play may be all that are needed. Others may require special exercises and playthings. Still others may need braces or other aids to help them move about better, do things more easily, or keep their bodies in healthier, more useful positions. Those who are severely paralyzed may be helped most by a wheelboard (trolley) or wheelchair.



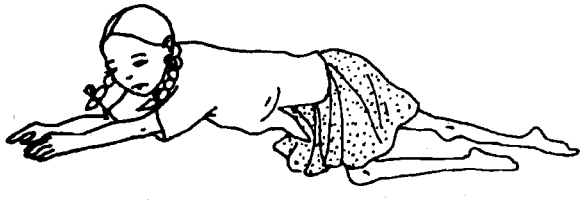
For this child, walking provides exercise that stretches his legs and feet, and prevents contractures. (Tilonia, India).

Every child needs to be carefully examined and evaluated in order to best meet his of her particular needs. The earlier you evaluate a child's needs, and take steps to meet them, the better.

Unfortunately, in most areas, where polio is still common, village rehabilitation programs do not exist or are just beginning. Many children (and adults) who have been paralyzed for a long time already have severe deformities or joint contractures. Often these must be corrected before a child can use braces or begin to walk.

Because contractures are such a common problem, not only with polio but with many other disabilities, we discuss them separately in the next chapter. **Before evaluating a child with polio, we strongly suggest you read Chapter 8 on contractures.**

Here are 2 true stories of what often happens in a village when a child gets polio.



Vimla's legs became paralyzed when she was only one year old. Because her paralysis was severe, she could not stand. She would always sit around the house. And when she had to get from one placeto another she would crawl on her hands and knees. Her parents did not know about physiotherapy and there was no rehabilitation centre nearby. As a result she had severe contractures of her hips and knees.

Vimla's paralysis and inability to walk, was to them a cruel act of fate – which had to be accepted. As Vimla grew older however, it became more and more difficult and socially embarrassing for her to move from one place to another. For 20 years Vimla did not stand or walk. She had to be operated at both hips, both knees and was in plaster for almost three months before her limbs could be straightened out to fit a caliper. Her brother helped her out with her exercises at home. Finally Vimla was made to stand. She had stood on her feet for the first time after 20 years!

Murugan's family lives in a small village, Muttur Palapadi, with only 20 households. Both his parents work as unskilled labourers on the fields of big land owners and earn a daily wage.

Murugan was 4 months old when he got fever for 3 days. His mother took him to a doctor who gave him an injection in his left leg. His legs became paralyzed.

Murugan's parents were so upset that they rushed to another doctor who told them that the child had polio. Then started a long search for doctors, healers and hospitals who would heal the child.

At first, they went to Katpadi, 80 km. away from their village to meet a healer, and then to the big city of Madras where they met another doctor. The doctor gave them some medicine with the assurance that their child would be cured. But nothing happened. In desperation, the parents then went to Kanjipuram to consult a healer. Twice they were given a bottle of specially prepared oil to rub on the child's leg. But there was no improvement.

Still hoping against hope, the parents took the child to many more doctors and healers. They got many more medicines, oils and went through many more religious ceremonies. At the end of it all they had exhausted all their savings and spent over 10,000 rupees.

In this time, Murugan got contractures of the hip, ankle and knee. He would not walk, talk or smile. Now he was 5 years old.

It was around this time that Murugan's parents heard of the Gandhi Rural Rehabilitation Centre at Alampondi, which had started very near their village. Here, they met workers trained to look after children with polio.

Murugan was started off on exercises. He and his mother would come every Saturday to the Centre to learn more exercises and practice the ones they were taught to do at home. Slowly, there was some improvement. But some of Murugan's contractures were so bad that they need to be operated. With the help of the rehabilitation centre, Murugan was operated upon at a district hospital. His mother was taught how to care for him after surgery.

Today, Murugan is able to go to school with a smile on his face.

PROGRESS OF A CHILD WITH POLIO: THE CHANGING NEEDS FOR AIDS AND ASSISTANCE

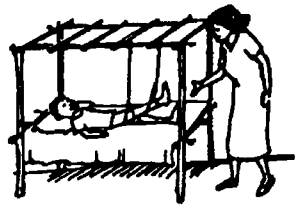
1. **exercises to keep full range of motion**, starting within days after paralysis appears and continuing throughout rehabilitation



2. **supported sitting** in positions that help prevent contractures



3. **active exercises** with limbs supported, to gain strength and maintain full motion

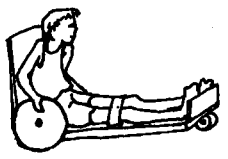


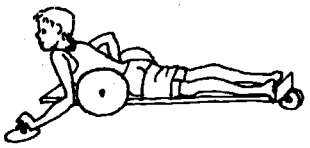
4. **exercise in water–walking, floating, and swimming, with the weight of the limbs supported by the water**

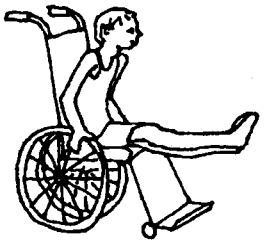


Do not let the child go unsupervised in the water.

5. **wheelboard or wheelchair** with supports to prevent or correct early contractures.







Note: these also provide good arm exercise in preparation for walking with crutches

6. **braces** to prevent contractures and prepare for walking



7. **parallel bars** for beginning to balance and walk



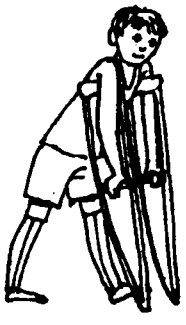
8. **walking machine or 'walker'**



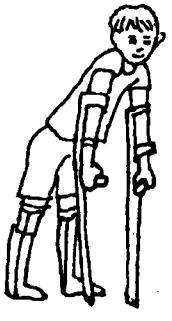
9. **crutches modified as walker** for balance and extra support



10. **under arm crutches**



11. **forearm crutches** and perhaps in time . . .



12. **a cane** or no arm supports at all



Warning: A single cane (lathi) or a single **crutch** is often used by people who have paralysis only in one limb. Quite often they wind their paralyzed limbs for support around the cane or crutch. This encourages contractures of the hips and knees and should be avoided.



Photo: Mathew Varghese

Note: These pictures are only an example – but most of the steps are necessary for many children. Children who begin rehabilitation late may also have contractures or deformities requiring corrective steps not shown here.

EVALUATING A CHILD'S NEEDS FOR AIDS AND PROCEDURES

Step 1: Start by learning what you can through talking with the child and family (see Child's History, p. 39 to 40). As you do this, **watch the child move about.** Observe carefully which parts of the body seem strong, and which seem weak. Look for any differences between one side of the body and the other – such as differences in the length or thickness of the legs. Are there any obvious deformities, or joints that do not seem to straighten all the way? If the child walks, what is unusual about the way she does it? Does she dip forward or to one side? Does she help support one leg with her hand? Is one hip lower than the other? Or one shoulder? Does she have a humpback, a swayback, or a sideways curve of the back?

These early observations will help you know what parts of the body you most need to check for strength and range of motion. Often, by watching a child you can begin to get an idea about what kind of aids or assistance may help. For example:

Amina appears to have severe paralysis affecting both legs and her right arm. Weakness in her *trunk* (main part of the body) appears to have caused a severe S – shaped curve of the spine.

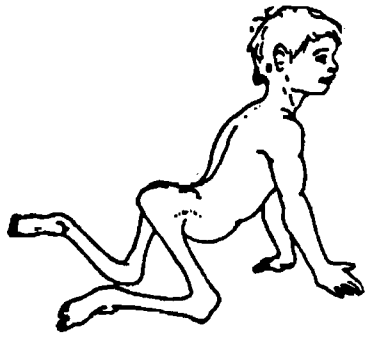


She will probably never walk, and will need a wheelchair or wheelboard.

You may want also to make her a body brace, or help her in other ways to sit more upright and try to keep the spine from bending more.



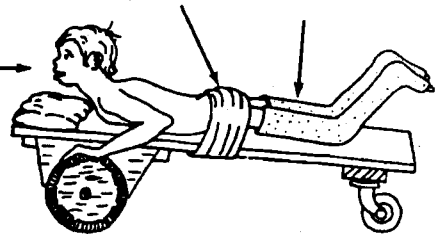
Raju appears to have severe paralysis in his legs and hips. It looks as if his hips, knees, and feet cannot straighten (contractures). Weak stomach muscles and severe hip contractures may be the cause of his swayback.



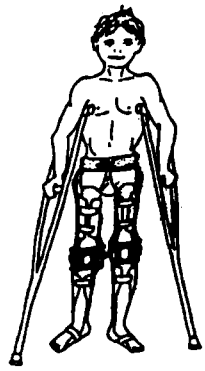
Because his arms look strong. Raju will probably be able to walk with crutches and leg braces. But first his contractures must be straightened.

strap to gradually straighten hips

casts to straighten knees and ankles



If the contractures cannot be straightened by gradual stretching, he may need surgery.



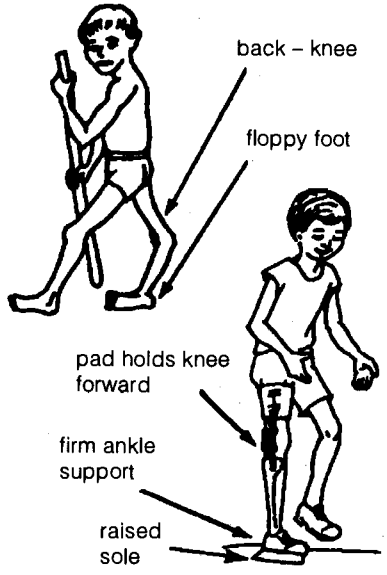
Because of hip weakness, he may need long leg braces with a hip band.

Titu used to walk around the village with a stick. Though he had weakness of both thigh muscles, he was able to lock his knees backwards in order to bear weight on it. This back kneeing had become more and more extreme as the cords behind the knees stretched. His parents noticed that gradually both his legs were beginning to look like parts of a semicircle. They were now worried. How would Titu go to school or help in the fields?.

Finally a village volunteer took Titu to a polio camp – at the stage when he could not even stand on his legs. Titu's knees had to be operated and he was able to walk once again with long leg braces in both his legs.

HAD TITU COME EARLIER TO A CAMP, or had a health worker spotted Titu earlier, **surgery could have been avoided.** He might have been able to walk without a stick if he used a below – knee brace to stabilize his foot. (See p. 670)

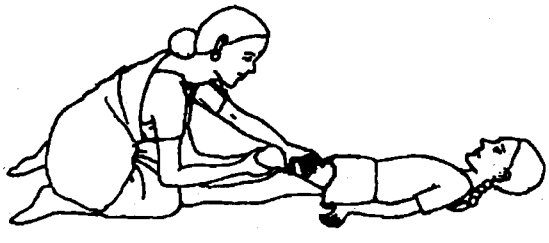
But the back–kneeing may have become worse and worse until he could not walk. So probably he should have had long leg braces. These braces might have allowed his knees to bend backward just a little for stability – so that no knee lock was needed.



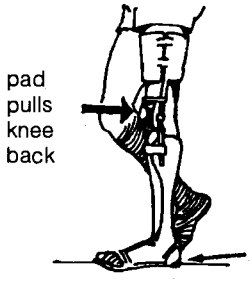
Gita leans forward and pushes her weak left thigh with her hand when she walks. Her left knee cannot quite straighten. Her weak leg looks a little shorter than the other.



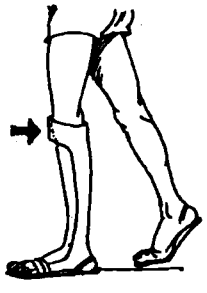
Exercises to get her knee straighter or so it can bend very slightly backward may be all that is needed for Gita to walk without using her hand.



Or she may need an above – knee brace with a strap to pull the knee back.



Or she may only need a below – knee brace that helps push her knee back.



The brace bends the foot down just a little, so that by bearing weight on toes (rather than heel) her knee is pushed back.

To get a better idea about which of the three solutions may work best for Gita you will need to do a careful physical examination, testing range of motion and muscle strength of the hip, knee, and ankle joints.

Step 2: This is the **physical examination.** It should usually include:

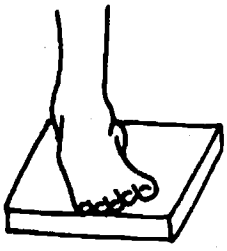
1. **Range – of – motion testing,** especially where you think there might be contractures. (See "Physical Examination," p. 29 to 31, and "Contractures," p. 79 and 80.)
2. **Muscle testing,** especially of muscles that you think may be weak. Also test muscles that need to be strong to make up for weak ones (such as arm and shoulder strength for crutch use). (See p. 29 and p. 32 to 35.)
3. **Check for deformities:** contractures; dislocations (hip, knee, foot, shoulder, elbow); difference in leg length; tilt of hips; and curve or abnormal shape of the back. (See p. 36.)

Step 3: After the physical exam, **again observe how the child moves or walks.** Try to **relate her particular way of moving and walking with your physical findings** (such as weakness of certain muscles, contractures, and leg length). (For an example, see p. 78.)

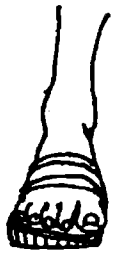
Step 4: Based on your observations and tests, try to **figure out what kind of exercises, aids, or assistance might help the child most.** Consider the advantages of different possibilities: benefit, cost, comfort, appearance, availability of materials, and whether the child is likely to use the aid you make. Ask the child and parents for their opinions and suggestions.

Step 5: Before making a final brace or aid to fit the child, if possible **test to see how well it may work** by using a temporary aid or old brace from another child. For example,

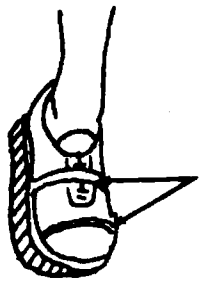
if a child's ankle bends over to the outside like this....



. . . a lift on the outer side of the sole like this, may help to keep the foot straighter.



But *before* nailing and glueing in the lift, quickly make a trial one of cardboard or something else and fasten it temporarily to the sandal or shoe with tape or string. Then have the child walk.



Note: For a few children, a lift like this will help. For many it will not.

Ask the child what she thinks.

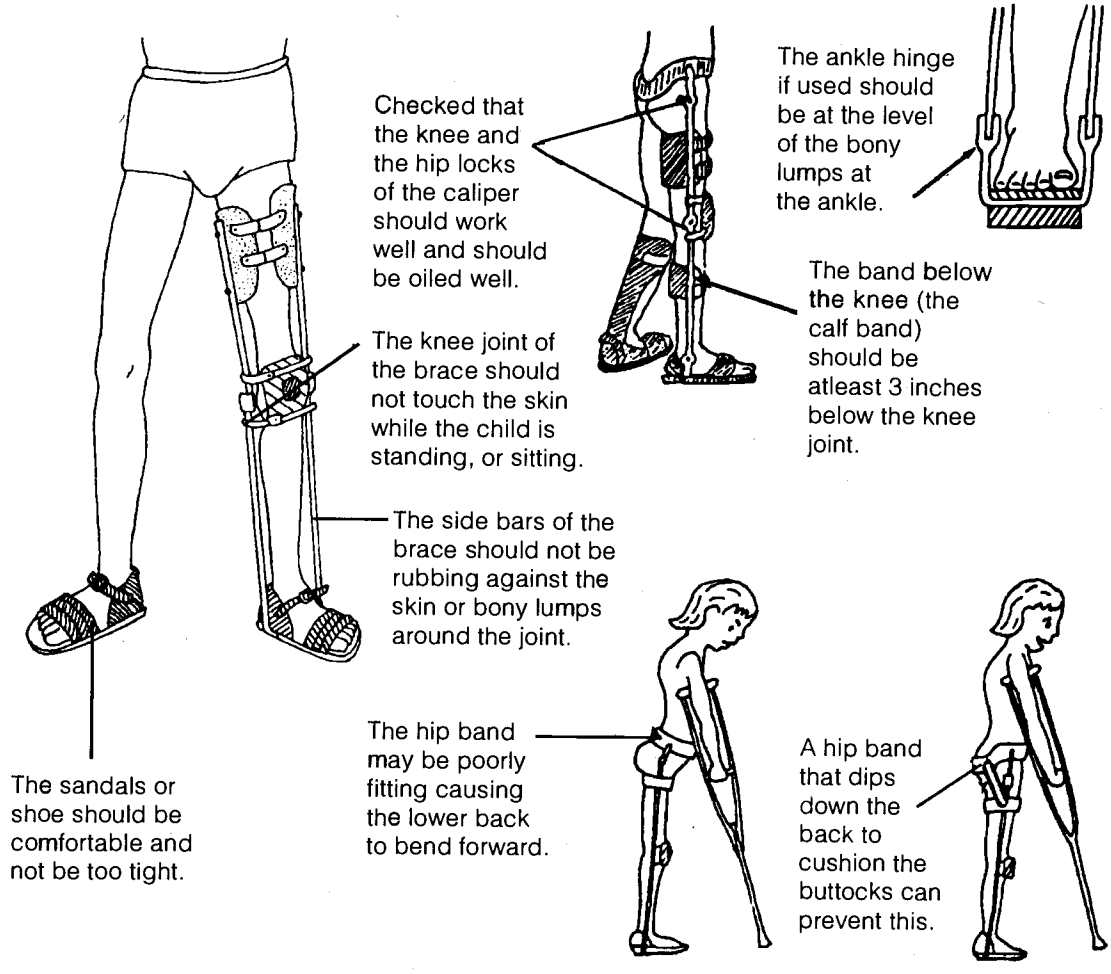
Step 6: After the child, her parents, and you have decided what kind of brace or aid might work best, **take the necessary measurements and make the brace or aid.** When making it, once again it is wise to put it together temporarily so that you can make adjustments before you rivet, glue, or nail it into its final form. (See p. 660.)

Step 7: Have the child **try the brace or aid for a few days** to get used to it and to see how well it works. Ask the child and parents if it seems to help. Does it hurt? Are there any problems? How could it be improved? Is there something that might work better? Make what adjustments are necessary. But remember that no brace or aid is likely to meet the needs of a child perfectly. Do the best you can.

Children may be fitted with aids in different situations. If there is a rehabilitation centre in the village or nearby, the child and his family may be able to spend 3–4 days at the centre so that the aid is fitted and the adjustments made.

Often, however, braces (calipers) are fitted in hospitals or camps which are far off from the village or locality where a child may be living and parents may not be able to stay at the hospital or camp for more than a day.

Parents and family members can learn to check if a brace fits or not.



For more details see Chapter 59.

Check the child's braces for their fitting every six months. The child who is growing fast will probably have outgrown her braces.

A child when first fitted with a brace will often not accept it even if she and her parents have been explained about it and even if the brace fits perfectly. It has been seen that if a child can manage to walk without braces she will prefer to do that. Let us accept it, the conventional braces are ugly and heavy and highlight the fact that the child has an impairment. The child is required to wear shoes with these braces and traditionally, children in the villages or urban slum areas do not wear shoes. Young girls often reject braces because they cannot wear their traditional dress with it.

There are other reasons also. The child may have never walked in her life and walking with a new brace may be painful and uncomfortable. Except for special lightweight braces she does need a lot of energy to carry the brace around. With continued use, the child may get used to all this. Don't be disheartened if the child cries in the beginning. A little patience and encouragement will help the child during the breaking in period.

Step 8. Surgery is often another step that the child may have to take. It is a step that has to be taken when contractures and deformities have become two severe to be straightened out with proper positioning, exercises and plaster casts.

Surgery is usually performed if it can help a child who cannot walk, to stand and walk; to reduce the size of the braces that the child uses; or to help him walk without them. Sometimes, surgery may also help reduce the limp of a child who though she is walking without aids, has an ugly limp.

> ***Caution:*** Surgery can not bring back power to weak muscles. It can not bring back bulk to a wasted limb. Surgery is not the best option for a child with polio.
> **IT IS BETTER TO PREVENT CONTRACTURES AND DEFORMITIES FROM OCCURRING.**

After surgery, parents and family members of the child can remember that . . .

- The wound **should not get** wet and the dressing should not get wet with urine or water. The part where surgery is done can be protected with a small polythene sheet from a shopping bag.
- Stitches are usually removed between 10 –14 days. Usually no dressing is required if the wound is clean.
- If the child has **temperature** or there is **excessive pain** or **swelling** or **discharge** at the operated place then the wound needs to be inspected. May be there is a local infection.
- There are **no dietary restrictions** when the wound is healing. Sometimes parents feel that milk and milk products should not be given to the child as these may lead to pus formation. On the other hand milk and milk products do good by providing proteins to the child.



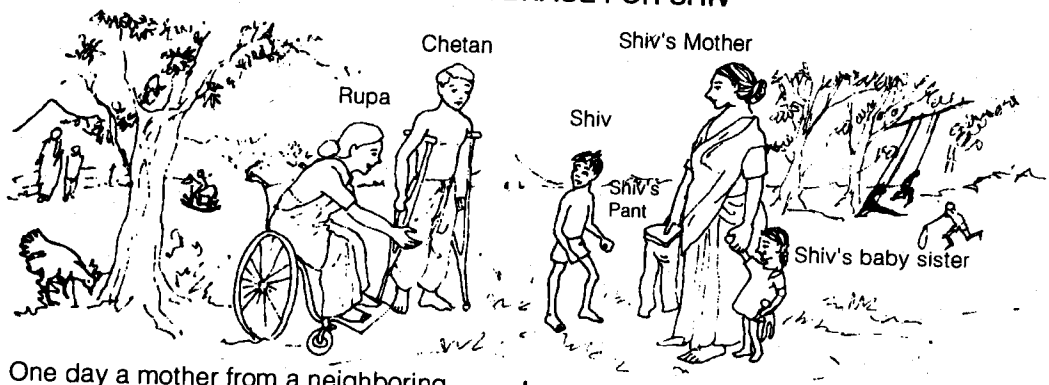
Photo : Mathew Varghese

This child's contractures have become so severe that he is unable to straighten his legs. To get from one place to another, he has to crawl on his hands and knees. He may have to undergo surgery to straighten his legs, After surgery proper positioning and exercises are very important to prevent his legs getting back to the severe contractures once again.

> ***WARNING:*** Before deciding on any aid or procedure, carefully consider its advantages and disadvantages. For example, some deformities may be best left uncorrected because they actually help the paralyzed child stand straighter or walk better (see p. 643). And some aids or braces may prevent a child from developing strength to walk without aids (see p. 638). **Before deciding what aid or procedure to use, we suggest you read Chapter 57, "Making Sure Aids and Procedures Do More Good Than Harm."**

Here is a story of how workers in a small village rehabilitation program figured out what kind of aids a child needed. **How many of the steps we have just discussed did they follow? Was each step important?**

A STORY: A BRACE FOR SHIV

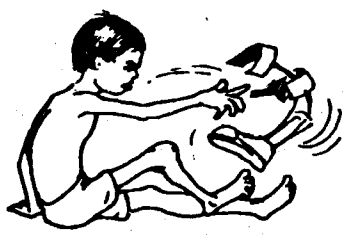


One day a mother from a neighboring village arrived at the village center with her 6 year old son, Shiv. Rupa and Chetan, 2 of the village rehabilitation workers, welcomed them warmly. Learning that Shiv had polio as a baby, they asked him to walk, and then to run, while they watched carefully. Shiv limped a lot and one leg looked thinner and shorter. With each step it bent back at the knee.

"He walks quite well, really," said Rupa. "But he has to 'lock' his knee back in order to put weight on it. That knee is going to keep stretching back and some day it will give out."

"A long – leg brace would protect his knee," suggested Chetan.

"Oh, please, no!" said Shiv's mother. "A year ago we took Shiv to the city and the doctors had a big metal brace made for him. It cost so much we are still in debt! Shiv hated it! He would always take it off and hide it. We tried and tried to get him to use it, but he wouldn't."



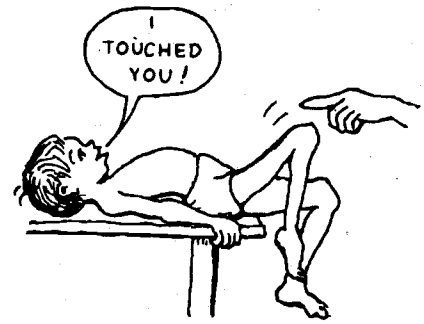
"That's not surprising," said Rupa."Often a child who can walk without a brace will refuse to use one–even if he walks better with it. We could make him a long–leg brace out of plastic. It would be much lighter. What do you say, Shiv?" Shiv began to cry.

"Don't worry, Shiv. May be we can do something simpler," said Rupa. "But first let's examine you, okay?" Shiv nodded.

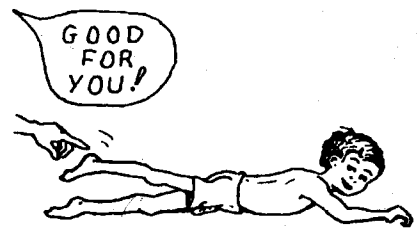
On muscle testing Shiv, they found he could not straighten his knee at all. But he had fair strength for bending his knee back.



and his hip forward.

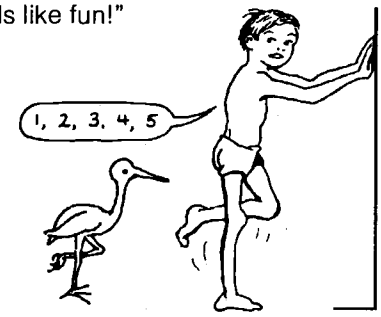


and good strength for bending his hip back.



"With the hip and thigh strength he should almost be able to stand on that leg without the knee bending back," said Rupa. "Shiv, let's see you try it like this. Pretend you're a stork!" For a moment Shiv could do it.
"Good!" said Rupa. "Every day stand like that and see how high you can count without letting your knee go back. Every day try to beat your old record! Okay?"

"Okay," said Shiv.
Sounds like fun!"



"The stork exercises may help," said Chetan. "But I still think he needs a brace. At least at first."

We must weigh the advantages against the disadvantages," said Rupa. "A long-leg brace would keep his knee straight. But it could weaken the muscles he needs to strengthen. Since the brace would keep his leg from bending back, he wouldn't have to use his muscles to do it.

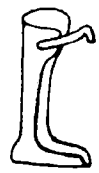


A long - leg brace might weaken the muscles Shiv needs to strengthen.

"On the other hand, we might try a short-leg brace that holds his foot at almost a right angle. Then, to step flat he will have to keep his knee nearly straight.
It could help him strengthen his behind-the -thigh muscles.

"Let's try it!" Everyone agreed, except Shiv.

short-leg plastic brace

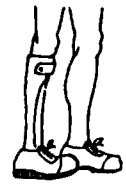


Chetan brought someone's old, lower-leg plastic brace and showed it to Shiv. "See how it will fit right around your leg. It isn't heavy at all. Lift it! And no metal joints to get in the way! What do you say? Do you want to try it?"

I guess so," said Shiv.

When the brace was made, they tested it. Shiv said he liked it. At first, when he tried hard, he could walk without bending his knee back. But after a few days, his mother complained that often he would walk, or even stand, with his knee bent way back as before, and his toes in the air, like this.

"WE THOUGHT IT WOULD WORK LIKE THIS...."

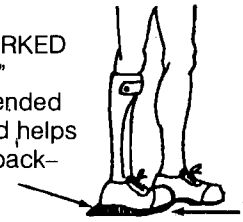


"BUT IN FACT IT WORKED LIKE THIS."



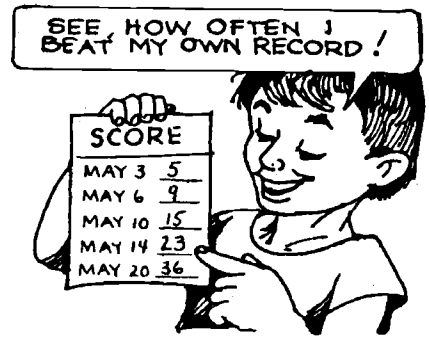
"I have an idea," said Chetan. "Why don't we let the heel stick out behind the shoe. That way, when he steps, his weight will come well forward of the back of his heel. This should help bring his foot down and his knee forward."

They tried it, and most of the time (especially when he was reminded) Shiv walked without letting his knee bend back much.



At home Shiv's mother encouraged him to do his stork exercises. As his muscles grew stronger, he began to walk without bending his knee far back-even in active play!





"WILL MY CHILD EVER BE ABLE TO WALK?"



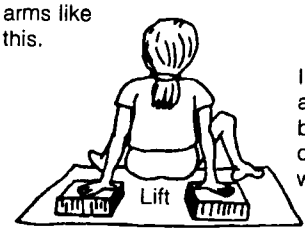
This is often one of the first questions asked by the parents of a disabled child. It is an important question. However, we must help parents realize that other things in life can be more important than walking (See p. 103).

If the child whose legs are severely paralyzed by polio is to walk, generally she will need at least 2 things:

1. **fairly strong shoulders and arms** for crutch use
2. **fairly straight legs (hips, knees, and feet).** (It is important to correct contractures so that the legs are straight or nearly straight before trying to adapt braces for walking.)

To evaluate a child's possibility for walking, always **test arm and shoulder strength:**

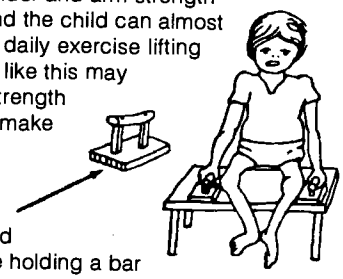
Have her try to lift her body weight off the ground with her arms like this.



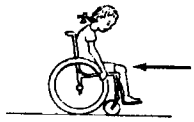
If she can easily lift up and down several times, she has a GOOD chance of being able to walk using crutches.

If her arms and shoulders are so weak she cannot begin to lift herself, her chances for crutch walking are POOR.

If her shoulder and arm strength is FAIR, and the child can almost lift herself, daily exercise lifting her weight like this may increase strength enough to make crutch use possible.

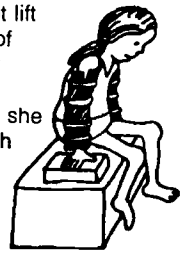


Having the child lift herself while holding a bar like this will also help strengthen her hands and wrists for crutch use.



Pushing herself in a wheelchair or wheelboard (trolley) is a practical way to strengthen shoulders, arms, and hands.

If the child cannot lift herself because of weak elbows, put simple splints on her arms to see if she can lift herself with these.



If she can lift herself with the elbow splints, maybe she can u crutches that give elbow support.

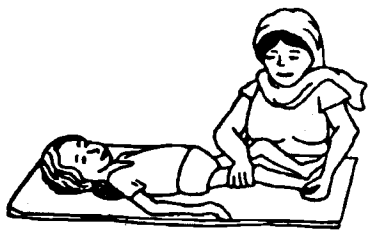


If she is fat she should lose weight. This will make walking on weak limbs much easier.

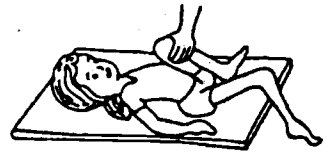


Now check how straight the legs will go. (See range-of-motion testing, p. 29)

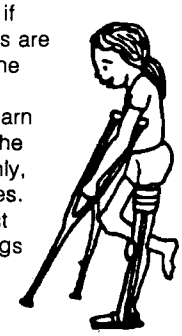
If the hips, knees, and feet can be placed in fairly straight positions, chances for walking soon with braces are good (if arm strength is good).



But if the child has much contracture of the hips, knees or feet, these will need to be straightened before she will be able to walk.



Sometimes if contractures are severe in one leg only the child can learn to walk on the other leg only, with crutches. But it is best with both legs whenever possible.



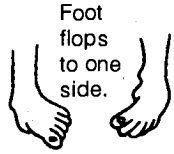
For correction of contractures, see Chapters 8 and 60.

After checking arm strength and leg straightness, the next thing to **check is the strength in the ankles, knees, and hips.** This will help you decide if the child needs braces, and what kind.

A child with a foot that hangs down (foot drop), **or flops to one side** may be helped by a below-knee brace of plastic or metal.

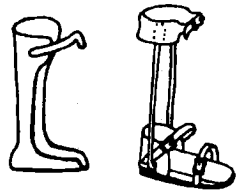


Foot drop: he cannot lift his foot.

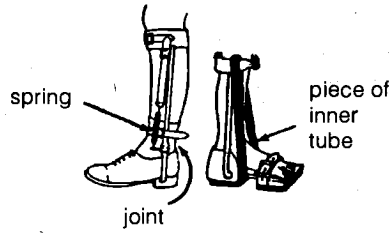


Foot flops to one side.

PLASTIC METAL

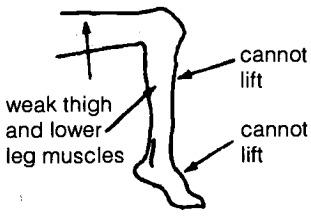


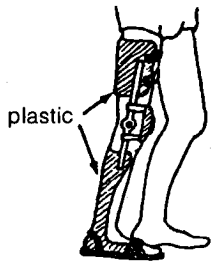
For foot drop, you can make a brace that lifts the foot with a spring or rubber band. (See p. 665.)

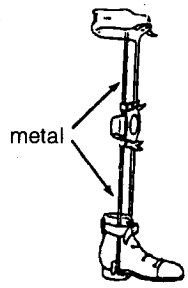


The kind of brace you choose will depend on various factors, including cost, available skills and materials, and what seems to work best for the particular child. **Advantages and disadvantages of different kinds of braces, and how to make them, are discussed in Chapter 59.**

A child with a weak knee may need a long-leg brace of plastic or metal.

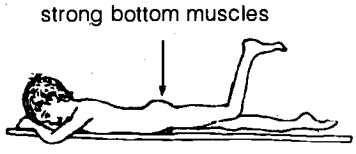






Upper-leg braces may be made with or without a knee joint that locks straight for walking and bends for sitting. Different models are discussed in Chapter 59.

Note: **Not all children with no strength to straighten the knee need long-leg braces:** a child with strong bottom (buttock) muscles may be able to walk without a brace.



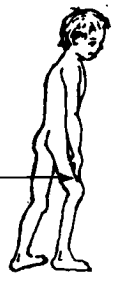


A child who has FAIR bottom (buttock) strength and a straight knee may be helped enough by a lower leg brace that pushes the knee back.



brace pushes knee back

Slightly downward angle of a stiff brace causes it to push the knee backward when weight bearing.



A child with weak bottom muscles may walk with one hand pushing on the weak thigh.

Or he may walk by bending the knee back to 'lock' it for weight bearing.



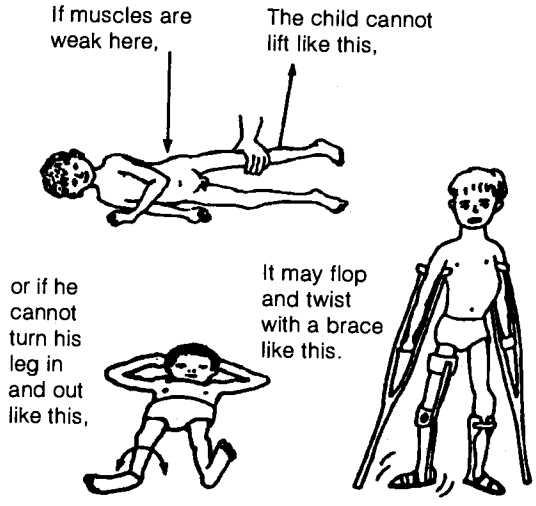
If a child has a contracture and cannot walk with his knee straight, correcting the contracture until his knee bends very slightly backward may allow him to walk better.

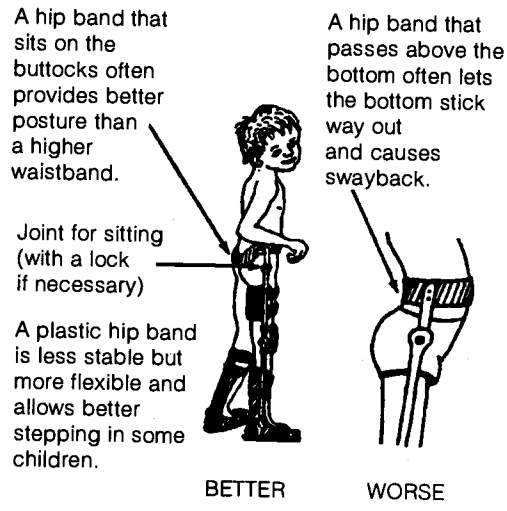


CAUTION: A stiff foot with a moderate tiptoe contracture may help push the knee back, just like a stiff brace. Correcting the contracture may make walking more difficult or impossible, so that a brace is needed where none was needed before. (See Chapter 57.)

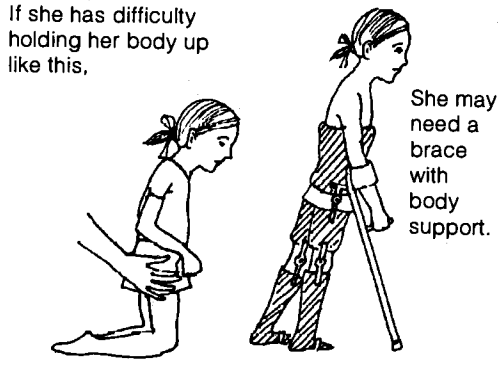
A child with very weak hip muscles may find his leg flops or twists about too much with a long-leg brace.

He may need a brace with a hip band to help stabilize the leg at the hip.





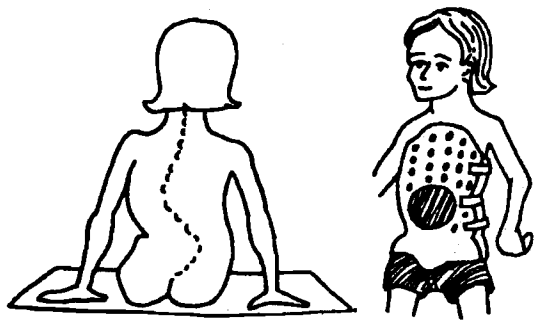
A child with weak body and back muscles, who cannot hold up her body well, may need long-leg braces attached to a body brace or body jacket.



Note: Often a child at first may need a hip band or body jacket to help stabilize her for walking. A few weeks or months later she may no longer need it.
Removing it may help the child gain more strength and control. It is **important to re-evaluate the child's needs for bracing periodically.**

Take care to use no more bracing than is needed.

A child whose backbone is becoming seriously curved may benefit from a body brace (or in severe cases, she may need surgery).



If necessary, the body brace can be attached to long-leg braces as shown above.

More information on spinal curve can be found in Chapter 20. For information on how to make body braces and jackets, see Chapter 59.

PREVENTION OF POLIO

- **Vaccinate** babies with polio vaccine. Follow the immunization schedule as closely as you can.

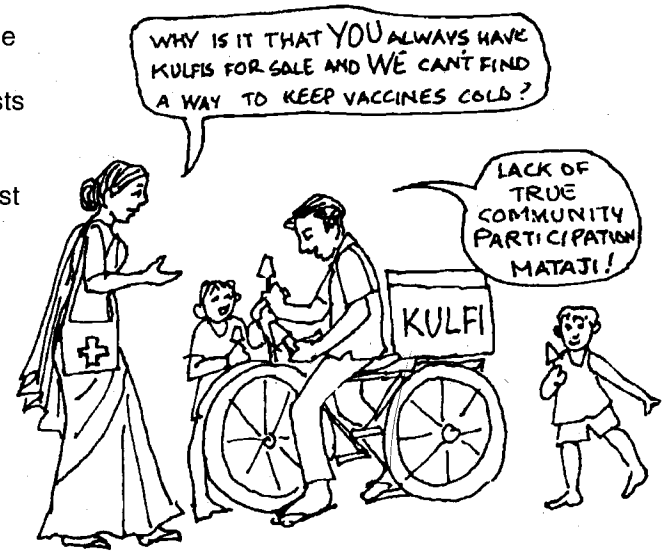
The polio vaccine is given
- at birth
- 6 weeks
- 10 weeks
- 14 weeks
- 1–1/2 years (Booster)

POLIO VACCINE, the best protection – if it has been kept cold continuously!



Children born in institutions are normally immunized at birth. A child born in the home or community must get the first dose by the time she is six weeks old. Be sure they get three doses of the vaccine by the time they are 14 weeks old.

- **Vaccinate as many children in the community as possible.** The vaccine given by mouth is alive. So, if most of the children are vaccinated, the live vaccine will spread to children who have not been vaccinated, and protect them also. However, often it happens that in some districts or areas where a large number of children are immunized there may be pockets or areas where children are not immunised. If a polio epidemic breaks out then it is likely to endanger the rest of the community also. These pockets will always run the risk of becoming the focus of infection. Therefore, it is in the interest of the community that there are no pockets or areas where children remain unvaccinated.
- **Complete the Vaccination Schedule** Giving one or two doses of polio vaccine will not protect your child against polio. It is of utmost importance that the child gets all the doses of polio vaccine. If your child is older (2–3 years old) and not immunised you can still give her the vaccine. But it is more important that the child is protected when she is most vulnerable. Children between 7–28 months are in the "high risk group" for getting polio.
- **Try to keep the live polio vaccine frozen until** shortly before it is used. For up to 3 months it can be thawed and re-frozen. But it must be kept cold or it will spoil.
- **Seek community help** with vaccination and in keeping vaccine cold. Sometimes vaccines do not reach villages because health posts lack refrigeration. But often storekeepers and a few families have refrigerators. Win their interest and cooperation.



- To give best protection, **vaccinate the child when she does not have a fever or a cold or diarrhoea.** Vaccination should not be given when a cholera epidemic is on. But if by 3 months of age, the child has not been vaccinated, give her the polio vaccine even if she is a little sick. However, there is a chance that the vaccine may not work. if it is given when the child is sick (with a virus infection). Therefore, still try to give the complete series of 3 vaccinations and one booster later, when the child is not sick.

A larger number of vaccines get spoiled by the time they reach the children. Therefore, even in children who have been vaccinated, additional precautions are needed:

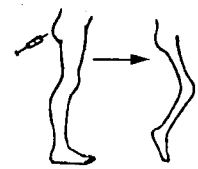
- **Breast feed** your baby as long as possible. Breast milk contains 'antibodies' that may help protect against polio. (Babies rarely get polio before 8 months old because they still have their mothers' antibodies. Breast feeding may make this protection last longer.)



BREAST MILK PROTECTS AGAINST INFECTIONS– INCLUDING POLIO

- **Do not give injections of any medicine to babies or children,** except when absolutely necessary, irritation caused by injected medicine can turn a mild, undiagnosed polio infection into paralysis. It is estimated that today 1 out of 3 cases of paralysis from polio is brought on by injections (see p. 21). DANGER!

DANGER!



INJECTIONS CAN CAUSE PARALYSIS FROM POLIO

- **Organize the people** and help out in popular campaigns to encourage **vaccination, breast feeding,** and **limited, sensible use of injections. Community theatre** and puppet shows are good ways to raise awareness on these issues. See Chapter 49.

UNDER THE IMMUNIZATION PROGRAM OF THE GOVERNMENT

- Vaccines are to be given free of cost to children.
- Vaccines should be available at all government health facilities.
- Every State sets a fixed date, fixed time and fixed place where children can get immunized.
- A women health worker is supposed to visit a village once every month on a fixed date to immunize children.

IMPORTANT INFORMATION ABOUT THE POLIO VACCINE

- The vaccine must be kept at a temperature between 2–8 degree C otherwise it will lose its potency.
- Normally there are 10 doses of the polio vaccine in one vial.
- Once the vial is opened the 10 doses of polio vaccine should be given as soon as possible to avoid change in temperature. If that can not be done, then the remaining doses should be thrown away.

WHAT CAN THE COMMUNITY DO TO ENSURE THAT THE CHILDREN ARE PROPERLY IMMUNIZED

- Members of the community can find out the date, the time and the place where immunization will take place and make sure that all children who need the vaccination go there. It is always better that a large number of children get vaccinated at one go so that the vaccine is not kept out at higher temperatures for a long time. Parents and the community can ensure that there are atleast 10 children to be vaccinated at one go.
- Check that the vaccines are stored in a refrigerated container. Under the National

Immunization Program every Public Health Centre must have a refrigerator and freezer in working order in which to store the vaccine. Even if you get vaccine from a private practitioner please check that he has a proper refrigerator to store the vaccine.

- If a child in your community has contracted polio it is important to inform the health worker or District Immunization Officer or the nearest Public Health Centre of this as soon as possible, so that polio control measures are intensified as soon as possible. The health worker will require the following details from you if effective action has to be taken.

Child's name
Age _____ Sex _____
Immunization status
Full address (so that she can be easily traced.)

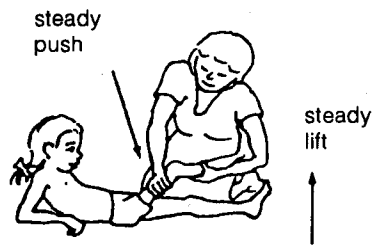
PREVENTION OF SECONDARY PROBLEMS

We have already discussed some ways to prevent new problems or complications in a child with paralysis. In summary, important measures include:

- **Prevent contractures and deformities.** Begin appropriate **range-of-motion** exercises as soon as the paralysis appears.
- At the first sign of a joint contracture, do **stretching exercises** 2 or 3 times a day–every day.

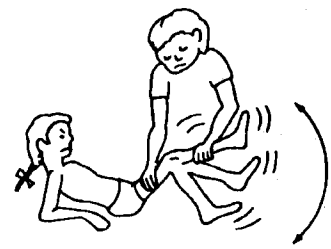
Stretching exercises work better if you stretch the joint firmly and continuously for a few moments,

CORRECT



instead of 'pumping' the limb back and forth.

WRONG



We emphasize this point because in many countries parents are taught the pumping method which does very little good.

For more details, see "Contractures," Chapter 8.

- **Evaluate the child's needs regularly, and change or adapt aids, braces, and exercises to meet her changing needs.** Too little or too much bracing can hold the child back or create new problems.
- **Be sure crutches do not press hard under the arms;** this can cause paralysis of the hands (see p. 481).



- **Try not to let the child's physical disability hold back her overall physical, mental, and social development.** Provide opportunities for her to lead an active life and take part in games, activities, school, and work with other children. PART 2 of this book discusses ways to help the community meet the needs of disabled children.

OTHER PARTS OF THIS BOOK THAT MAY BE USEFUL IN MEETING NEEDS OF A CHILD AFFECTED BY POLIO

Especially important chapters are marked with a star:

Physical examination, Chapter 4

Measurement of contractures and progress, Chapter 5

* Contractures, Chapter 8

Dislocated hips, Chapter 18

Spinal curve, Chapter 20

* Range–of–motion and other exercises, Chapter 43

Crutch use, wheelchair transfers, etc., Chapter 44

*

Community needs, social adjustment,

Growing up, PART 2, especially Chapters 48, 49, 53, 54

Making sure aids and procedures meet the

Child's needs, Chapter 57

* Braces and calipers, Chapter 59

* Correcting contractures, Chapter 60
Correcting club feet, Chapter 60

Special seating and wheelchairs, Chapters 65, 66, 67

Aids for walking, Chapter 64

For more information on polio, see References p. 769.

A BOY WITH POLIO BECOMES AN OUTSTANDING HEALTH AND REHABILITATION WORKER

Marcelo Acevedo was disabled by polio. He and his family lived in a village 2 days from the closest road. Village health workers from Project Piaxtla helped Marcelo get surgery for his knee contractures. After surgery he got braces and went to school. Then they trained him as a village health worker, and he returned to serve his village.



Marcelo at age 4, sitting with his older brother who was temporarily disabled when a tree fell on his leg.



Marcelo training at Project Piaxtla.

When PROJIMO was formed, Marcelo joined as a village rehabilitation worker. He studied brace-making as an apprentice in 2 brace shops in Mexico City.



Marcelo making a plastic leg brace.



Marcelo and other villagers make a plaster body mold of a young boy's chest. The child had polio and has a severe curve of the spine.



With his plastic body brace, made by Marcelo, the child can sit much straighter.

Marcelo is now one of the leaders in PROJIMO, and has gained respect of the whole village. He has recently married a village woman.

CHAPTER **8**

Contractures

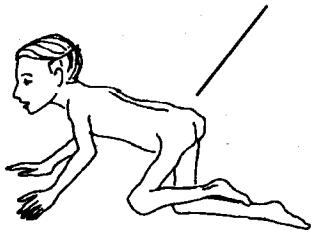
Limbs That No Longer Straighten

WHAT ARE CONTRACTURES ?

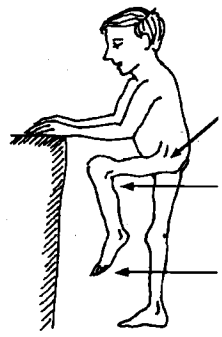
When an arm or leg is in a bent position for a long time, some of the muscles become shorter, so that the limb cannot fully straighten. Or shortened muscles may hold a joint straight, so it cannot bend. We say the joint has a 'contracture'. Contractures can develop in any joint of the body. For example:

1. Mahesh spent the first years of his life crawling because one leg was paralyzed.

Because he could not stand, he kept his hip and knee bent and his foot in a tiptoe position, like this.



2. In time, he could not straighten his hip or knee, or bend his foot up. He had developed a:

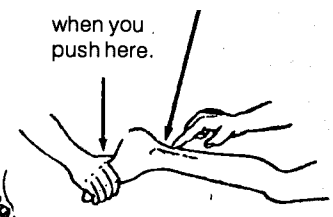


hip contracture

knee contracture

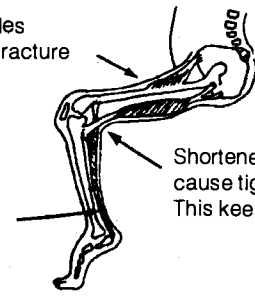
'tiptoe' contracture of the ankle

You can feel the tight ***cord*** here, when you push here.



3. Because of the contractures, Mahesh could not stand or walk, even with a brace.

shortened muscles causing hip contracture

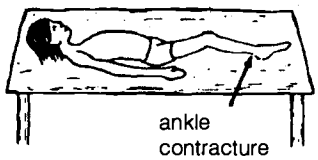


Shortened muscles-that-bend-the-knee cause tight cords behind the knee. This keeps it bent.

Shortened calf muscles cause a tight heel cord that keeps the foot in a 'tiptoe' position.

Contractures develop whenever a limb or joint is not moved regularly through its full range of motion. This is likely when:

- a very weak or sick child is in bed for a long time.



ankle contracture

- a paralyzed limb is kept bent or hanging.

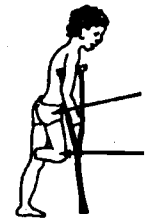
hip contracuture

knee contracture

ankle contracture



- a child with an amputation keeps joints bent.



hip contracture

knee contracture

- a child has joint pain that prevents her from straightening her joints.



contractures in:
- neck,
- shoulders,
- back,
- elbow,
- wrists,
- fingers,
- hips,
- knees,
- ankles,
- feet,
- toes,

Why is it important to know about contractures?


hand paralysis with contractures

- Most contractures can be prevented through exercise and other measures. Yet **in many communities, at least half of the physically disabled children already have contractures.**
- Contractures make rehabilitation more difficult. **Often they must be corrected before a child can walk or care for himself.**
- Correction of contractures is **slow, costly, and often very uncomfortable or painful.**
- It is best not to let contractures develop, and if they do begin to develop, to correct them as soon as possible. Early contractures often can be easily corrected at home, with **exercises** and **positioning.** Advanced, old contractures are much more difficult to correct, and may require gradual stretching with plaster casts, or surgery.

For all these reasons....

Every family with a disabled child should understand how contractures develop, how to prevent them, and how to recognize and correct them when they first begin.

Muscle imbalance – a major cause of contractures

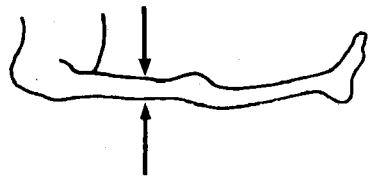
CP When the muscles that bend or pull a limb in one direction are much stronger than those that pull it in the opposite direction, we say there is a 'muscle imbalance'. When paralysis, painful joints, or spasticity (see p. 99) cause a muscle imbalance, contractures are much more likely to develop.

CP

WITHOUT MUSCLE IMBALANCE— CONTRACTURES LESS LIKELY

A leg that is completely paralyzed is not very likely to develop contractures. The knee may even straighten more than normal.

muscles equally weak on both sides



no contracture

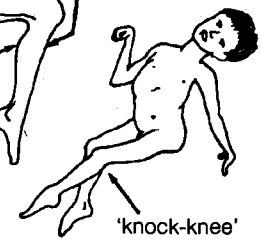
WITH MUSCLE IMBALANCE— CONTRACTURES MORE LIKELY

If the muscles that straighten the knee and lift the foot are very weak,

and the muscles that bend the knee and lower the foot are strong,

contractures are very likely to develop.

Muscle imbalance causing contractures can result from spasms, or spasticity, that increase the pull of certain muscles (cerebral palsy and spinal cord injury).



'knock-knee' contracture of hips

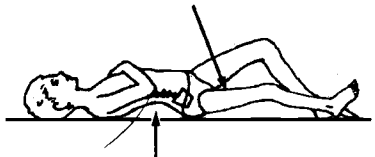
For example, the bent elbows and crossed legs of this child with spastic cerebral palsy can lead to contractures so that her legs cannot be spread apart or her elbow straightened.

To check for muscle imbalance, test and compare the strength of the muscles that bend a joint, and of the muscles that straighten it. (See muscle testing p. 32.)

EXAMINING THE CHILD FOR CONTRACTURES

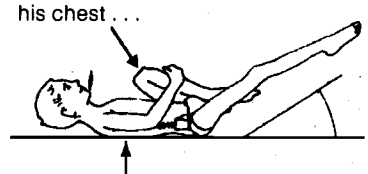
This is done through testing the **'range of motion'** of different joints, as described on p. 29 to 31. Most contractures will be obvious when you test for them. But hip contractures can easily be missed.

This child can lie with his right leg almost flat . . .



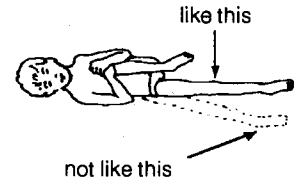
. . . by arching his back. You might think he has little or no hip contracture.

But if you test him with his other knee bent up to his chest . . .



. . . his back flattens and you can see the amount of contracture.

Be sure to test for contractures with the leg lined up straight.



Also ***be sure joints do not dislocate*** when you test for contractures, because this can fool you, too. For example:

This child's foot can rest on the ground,



only because it dislocates sideways.



tight heel cord



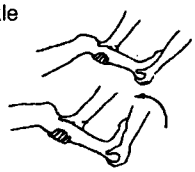
If you hold the foot so it does not dislocate, you will see that the ankle has a severe contracture.

How to tell contractures from spasticity

Spasticity (muscle tightening that the child does not control) is common when there is damage to the brain or spinal cord. (See p. 99.) It is sometimes mistaken for contractures. It is important to know the difference.

CP

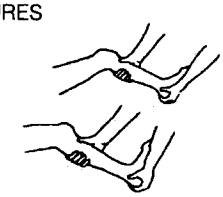
SPASTICITY of ankle joint



If at first it resists under steady pressure,

and then it **slowly yields** it is probably spasticity.

CONTRACTURES of ankle joint



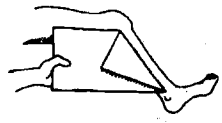
If it resists under steady pressure,

and **does not yield**, it is probably a contracture.

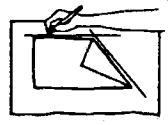
Spasticity often leads to contractures. For details, see p. 115 and 117.

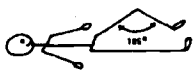
MEASURING CONTRACTURES

This can be done by folding a paper and measuring the angle, as shown here,



and then tracing that angle onto a record sheet.





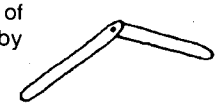
You can record your measurements with stick figures.

Or an easier, more fun way is to use a flexikin (see p. 45).

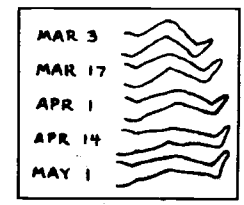
or use a 'compass'.



Or make a simple instrument of 2 thin pieces of wood joined by a bolt or rivet, tight enough so that they move stiffly.



By keeping a record of their child's progress, a family can see the results and is more likely to keep working hard at exercises to correct a child's contractures.



Can a contracture be straightened in the village?

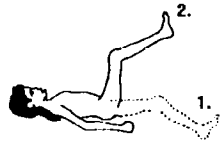
Contractures usually begin with shortening of muscles, causing tight cords (tendons). Later, the *nerves*, skin, and 'joint capsule' also can become tight. (A 'joint capsule' is the tough covering around a joint.)

When a contracture is only in the muscles and cords, it can usually be straightened by exercises and casts at a village rehab center, although sometimes this may take months. But if the contracture also involves the joint capsule, it is often much more difficult or impossible to correct, even with many months of using casts. Surgery may be needed.

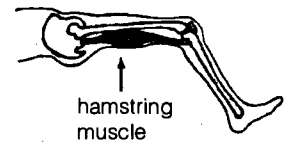
Note: If you find the information on this page hard to understand, do not worry. Come back to it later, when you meet very stubborn contractures.

TO TEST THE KNEE JOINT:

Check the range of motion of the knee with the hip straight and then bent.



Explanation: One of the main muscles that causes a knee contracture is the 'hamstring muscle', which runs all the way from the hip bone to the bone of the lower leg. This means that when the hip is bent, the tight muscles will bend the knee more.



If the knee straightens more when the hip is straight



than when the hip is bent,

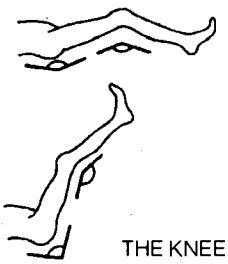


probably this is a **muscle contracture** (as short hamstring muscle).

THE KNEE BENDS MORE: **MUSCLE CONTRACTURE**

This can often be corrected in the village.

But if the knee straightens equally when the hip is straight or bent,



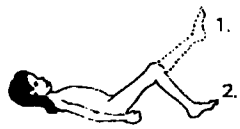
probably there is contracture of the joint capsule.

THE KNEE BENDS THE SAME: **JOINT CAPSULE CONTRACTURE**

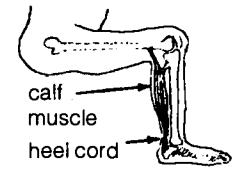
This often requires surgery.

TO TEST THE ANKLE JOINT:

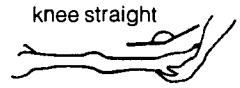
Check the range of motion of the ankle with the knee straight and then bent.



Explanation: One of the main muslces that pulls the foot to a tiptoe position runs from the thigh bone all the way to the heel. This causes the heel cord to pull more when the knee is straight than when the knee is bent.



If the foot pushes down more when the knee is straight



than when the knee is bent, it is a **muscle contracture.**



THE FOOT BENDS UP MORE: MUSCLE CONTRACTURE

This can often be corrected in the village.

But if the foot angle is the same when the knee is straight or bent,



there probably is a contracture of the joint capsule.

THE FOOT BENDS THE SAME: **JOINT CAPSULE CONTRACTURE**

This often requires surgery.

JOINTS THAT DO NOT MOVE AT ALL

If a joint moves only a little, the joint capsule may be very tight, or there may be a deformity in the bones. With exercises, try to gradually increase the movement.

If a joint does not move at all, the bones may be 'fused' (joined together). This often happens when there is a lot of pain and damage in the joint. When a joint has fused, exercise will usually not bring back motion. The only surgery that might help return joint motion is to put in an 'artificial joint' of metal or plastic. This surgery is very costly, and if the person is very active, the joint may not last more than a few years.

PREVENTION AND EARLY MANAGEMENT OF CONTRACTURES

Contractures can often be prevented by (1) positioning, and (2) range-of-motion exercises. (CP)

POSITIONING

If a child is likely to develop contractures or has begun to develop them, try to position her to stretch the affected joints. Look for ways to do this during day-to-day activities: lying, stitting, being carried, playing, studying, bathing, and moving about.

During a severe illness (such as acute polio), or a recent spinal cord injury, contractures can develop quickly. Therefore, early preventive positioning is very important:

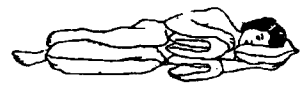
CORRECT



Put a pillow between legs to hold knees apart.

Lying and sleeping straight helps prevent contractures.

CORRECT

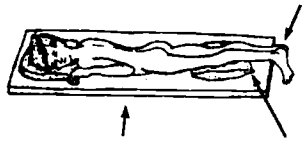


Also use pillows for side-lying to keep a good position.

WRONG



Lying and sleeping with the legs in a twisted or bent position causes contractures.



Letting feet hang over edge helps prevent ankle contractures.

Lying part of the time face down helps stretch hips backward

A pillow here helps stretch knees.



A foot board helps to prevent ankle contractures.



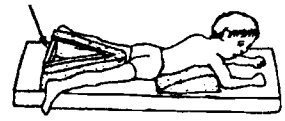
The foot support can be leaned forward a little so that the child can stretch his feet by pushing against it. (Be sure to pad it.)

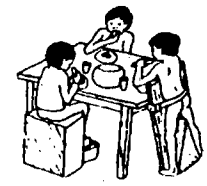


Support feet at right angles.

If knee contractures might develop, keep the knees straight as much as possible,

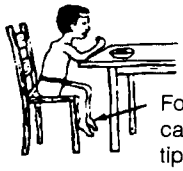
Leg separator if needed





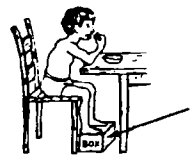
A child who spends most of the time sitting should spend part of the day lying or standing (on a frame if necessary). This will help prevent contractures of the hips and knees.

WRONG



Foot hanging can lead to tiptoe contractures.

BETTER



foot lifts



Figure out ways to help the child stay in contracture-preventing positions.

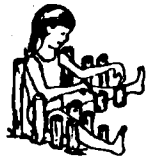
BEST



child-sized furniture

For a child with spasticity whose legs press together or cross, look for ways to sit, lie, or carry him with his legs separated. Here are a few examples.

For more examples of ways to prevent 'knock-knee' contractures, see p. 112.









(For more ideas about special seating and positioning, see Chapter 66.)

Exercises to prevent contractures

Just as cats, dogs, and many other animals stretch their bodies after they wake up, children often enjoy stretching their limbs and testing their strength. This is one of the purposes of play.



Daily stretching keeps the joints able to move smoothly and freely through their full range of motion.



Unfortunately, some children, because of illness, paralysis or weakness, are not able to stretch all parts of their bodies easily during their play and daily activities. If some part of their body is not regularly stretched or moved through its full range, contractures may develop.

To maintain full, easy movement of their joints and limbs, these children therefore need daily exercises that move the affected parts of their bodies through their full range of motion.



Range-of-motion exercises for the shoulder.

Range-of-motion exercises for each body joint are discussed in Chapter 43.

As much as possible, the child herself should try to move the affected part through its range of motion. Often the limb will be too weak and help is needed. But **be sure the child moves it as much as she can herself.**

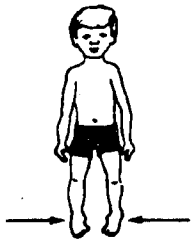


Have the child move the part as far as she can without help. Then help her to move it the rest of the way.

Where there is muscle imbalance, strengthening the weaker muscles can help prevent contractures. **examples of muscle strengthening exercises are on pages 158 to 161 and 476 to 480.**

As much as possible, try to **make exercises fun.**

A child whose feet tend to bend *inward* like this,



may benefit from exercises that bend them *out ward*, like this.



Walking on boards in a V-shape may provide similar stretching and be more fun.

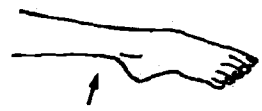


But going with father on the V-shaped paths to the bean fields may be even more fun–and it stretches his ankles more, because it is a long way.



FOUR WAYS TO APPROACH STRETCHING EXERCISES: To prevent (or help correct) contractures, exercises can be done in 4 different ways, depending on the needs and ability of the child. These 4 ways, shown on the next page, progress from **exercises where the child depends completely on help, to exercises that she does on her own as a part of everyday activity.**

FOUR WAYS TO DO EXERCISES THAT STRETCH A TIGHT HEEL CORD



1. Someone else moves the limb.



Often necessary – but not much fun

2. The child does his own exercises, but without using the muscles in the affected part.



(This may help to prevent a contracture but will not help much to correct it.)

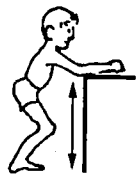
Here the child does his own stretching with some help from his mother.





Keep heels down.

Leaning against a wall stretches the feet more than standing upright does.



If the child is strong enough, bending the knees or touching the toes is a good way to stretch the muscles that cause a tight heel cord.



CAUTION: When doing these exercises, carefully **check to see that the foot is not dislocating to the side.**

If so, you should use Method 1, being careful to hold the foot in such a way that it does not 'cave in' to the side.



3. The child does the exercise – using muscles, of the affected part.

WITH ASSISTANCE:

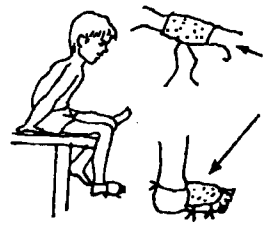
If the child has some strength to raise his foot, have him raise it as far as he can. Then help him to raise it as far as it will stretch.

Developing the muscles that lift the foot may help prevent contracture.



AGAINST RESISTANCE:

If the child has enough strength to raise his foot against resistance, he should do so. But be sure that the foot comes **all the way up.**



sand bag tied to foot

piece of old car or bicycle tire inner tube



4. The child does the exercise – during normal daily activities.

Figure out ways or aids so that the child can take part in ordinary activities that stretch muscles and prevent contractures.



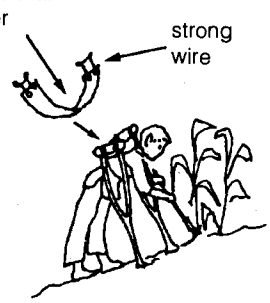
standing and walking uphill to stretch heel cords



picking vegetables

chest band that hooks over crutch top

strong wire





Sewing on a machine can exercise foot and combat contractures.



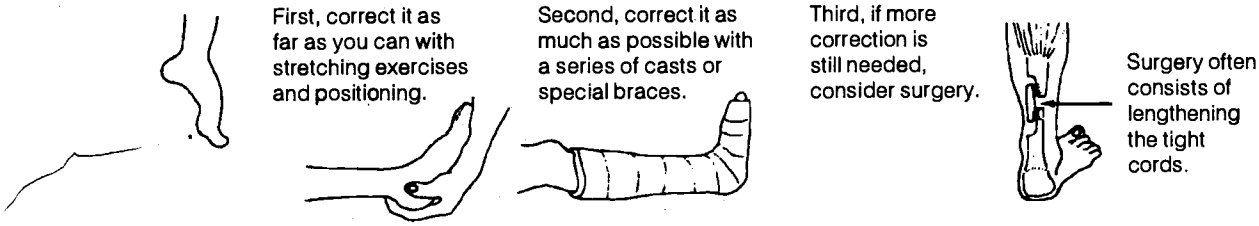
bar that permits child to squat and bend ankles

DIFFERENT METHODS TO CORRECT CONTRACTURES

- When contractures are just **beginning** to develop, **stretching exercises** and **simple positioning** may be all that is needed to correct them.
- When contractures are **more advanced,** stretching must be done steadily over a long time, using **fixed positions, casts, braces,** or **special equipment** that keep a continuous pull on the affected joints.
- When contractures are **old and severe,** correction by **surgery** may be needed.

Even when contractures are advanced, it is usually best to try to correct them as much as possible using simpler, less harsh methods first.

If a contracture is advanced:



First, correct it as far as you can with stretching exercises and positioning.

Second, correct it as much as possible with a series of casts or special braces.

Third, if more correction is still needed, consider surgery.

Surgery often consists of lengthening the tight cords.

Instructions for correcting contractures using plaster casts or braces are in Chapter 60.

CAUTION: Some **orthopedic** surgeons are quick to recommend surgery. However, we have found that many contractures often said to need surgery can be corrected in the village or home by exercise and casting or braces. In any case, **stretching exercises and bracing are often needed for a long time after surgery (or forever) to prevent the contractures from coming back.** Also, some contractures are best left uncorrected (see Chapters 43 and 57). When in doubt, consult an experienced physical therapist.

Exercises to correct contractures – 'stretching exercises'

These are similar to the range-of-motion exercises used to prevent contractures, except that steady, gentle but firm stretching is required:



1. Hold the limb in a steady, stretched position while you count slowly to 25.
2. Then gradually stretch the joint a little more, and again count slowly to 25.
3. Continue increasing the stretch in this way, steadily for 5 to 10 minutes. Repeat several times a day.

CAUTION: **To avoid damaging the limb, hold it near the joint, as shown. It is acceptable if the stretching hurts the child a little, but it should not hurt him a lot. If you want faster results, do not apply more force. Stretch the limb for longer and more times each day.**

In children who do not feel in their legs, take special care not to stretch forcefully. You could cause injuries.

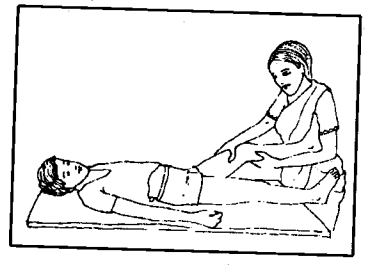
STRETCHING EXERCISE INSTRUCTION SHEETS

Some stretching exercises are done best using special techniques. Often they need to be done at home for weeks or months. You will find instruction sheets for the most frequently needed stretching exercises in Chapter 43, "range-of-motion and Other Exercises." They include:

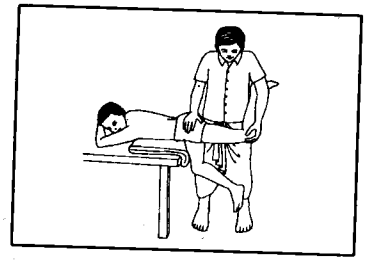
Stretching exercise for a **tight heel cord.** See p. 471.



Stretching exercise for a **bent knee.** **See p. 472.**



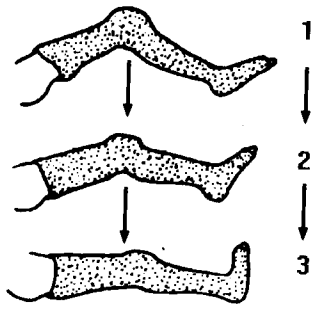
Stretching exercise for a **bent hip.** See p. 473



HOLDING A CONTRACTED JOINT IN A STRETCHED POSITION FOR LONG PERIODS

Chapter 60 discusses the use of casts, braces, and other aids to stretch difficult contractures. These include:

a series of plaster casts and wedges



Advantages:

- Holds leg in exactly the position you want it.
- Child (or parent) cannot easily remove it.
- Especially useful for difficult deformities that bend in different directions.

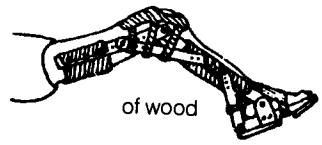
Disadvantages:

- Cannot be easily removed to check for sores, to bathe, and to exercise. (Therefore, casts should usually not be used on children with arthritis or children without feeling in their legs.)
- Hot in warm weather.
- Expensive (plaster bandage).
- Adjustments require trip to clinic or rehabilitation center.

adjustable braces



of metal and plastic



of wood

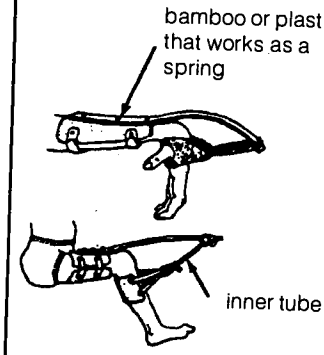
Advantages

- Can be adjusted by family at home.
- Can be easily removed to check for sores, for bathing, and exercise.

Disadvantages:

- More difficult to make and to fit well.
- Difficult to use on child with various deformities that go in different directions.
- Child (or parents) may remove and not use it.

elastic stretching devices



Advantages:

- Same as for adjustable braces, and also:
- Does not need frequent adjustment because it keeps pulling as joint stretches.

Disadvantages:

- Clumsy – gets in the way.
- Difficult to make so they work well.
- Often not good with spasticity.

HIP CONTRACTURES

Hip 'flexion' contractures (in which the thighs stay bent forward at the hips) are often difficult to straighten and require special techniques.

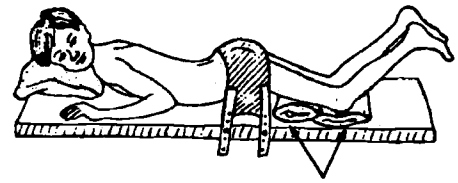
Advanced hip contractures like this often require **surgery.**



Less advanced hip contractures like this can sometimes be straightened using **positioning and straps.**



The child lies face down with a wide strap pulling his buttocks down.



cushion under thighs
(Avoid pressure on knees.)

The child should spend as many hours as possible each day in this position. And if possible, also at night. Knees should be checked for early signs of pressure sores every hour or so. (See Chapter 24.)

Life can be made more interesting for the child during the weeks or months of stretching by using a lying frame on which she can move about.

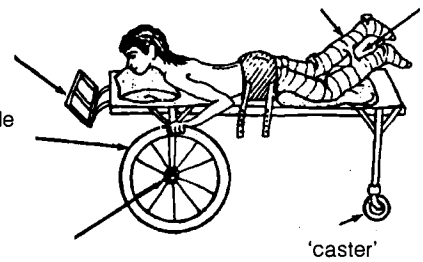
A rack or bookholder so she can play or read.

Casts to straighten knees and ankles

A bar fastened between the 2 leg casts helps keep them in a stable position (and also helps prevent contractures that pull the legs together).

For other designs see p. 746.

large bicycle wheels



'caster' rear wheels, for turns

extra strong axles and hubs (See p. 751.)

CAUTION: When stretching contractures this way, be careful to prevent pressure sores (bed sores), especially on the knees. If the child complains a lot, loosen the strap a little. For eating, bathing, toilet, and exercise she can be unfastened and moved into convenient positions. But it is best that she remain strapped down about 20 out of each 24 hours.

The child with more severe contractures at the hips may need to be strapped on an angled frame.

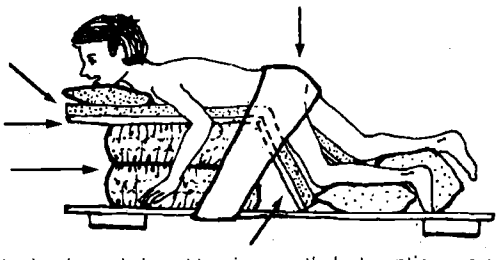
strap

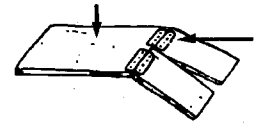
plywood or wood

sponge

wood frame

old tires or anything to lift body





Leather or canvas strips work as hinges that support legs.

For children with different angles of contracture in each hip, the 2 leg boards can be adjusted differently.

The angle of the leg boards is set to give gentle but continuous pressure against the thighs. As the contracture is gradually corrected, the angle is changed by raising the leg boards or by lowering the body board.

For additional information on contractures relating to different disabilities, aids, and equipment, see the INDEX under 'Contractures'. For methods to correct contractures, see Chapter 60.

Cerebral Palsy

CHAPTER 9

WHAT IS CEREBRAL PALSY?

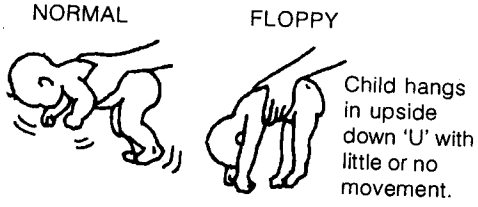
Cerebral palsy means 'brain ***paralysis***'. It is ***disability*** that affects movement and body position. It comes from brain damage that happened before the baby was born, at birth, or as a baby. The whole brain is not damaged, only parts of it, mainly parts that control movements. Once damaged, the parts of the brain do not recover, nor do they get worse. However, the movements, body positions, and related problems can be improved or made worse depending on how we treat the child and how damaged his or her brain happens to be. **The earlier we start, the more improvement can be made.**

In many countries cerebral palsy is the most frequent cause of physical disability. In other countries it is second only to polio. About 1 of every 300 babies is born with or develops cerebral palsy.

How to recognize cerebral palsy

EARLY SIGNS:

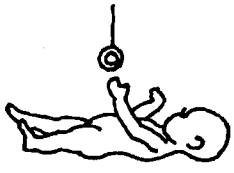
- At **birth** a baby with cerebral palsy is often **limp** and **floppy,** or may even seem normal.



- Baby may or may not breathe right away at birth, and may turn blue and floppy. Delayed breathing is a common cause of brain damage.
- **Slow development** Compared to other children in the village, the child is slow to hold up his head, to sit, or to move around.



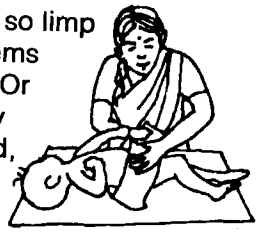
- He may not use his hands. Or he only uses one hand and does not begin to use both.



- **Feeding problems** The baby may have difficulties with sucking, swallowing and chewing. She may choke or gag often. Even as the child gets bigger, these and other feeding problems may continue.

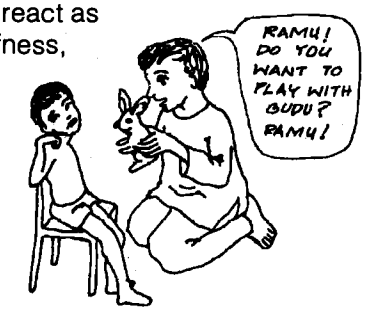


- **Difficulties in taking care of the baby or young child.** Her body may stiffen when she is carried, dressed, or washed, or during play. Later she may not learn to feed or dress herself, to wash, use the toilet, or to play with others. This may be due to sudden stiffening of the body, or to being so floppy she 'falls all over the place'.
- **The baby may be so limp that her head seems as if it will fall off. Or she may suddenly stiffen like a board, so that no one feels able to carry or hug her.**


Body stiffens like a board

- The baby may cry a lot and seem very fussy or 'irritable'. Or she may be very quiet (passive) and almost never cry or smile.

- **Communication difficulties** The baby may not respond or react as other babies do. This may partly be due to floppiness, stiffness, or lack of arm gestures, or control of face ***muscles.*** Also, the child may be slow in beginning to speak. Later some children develop unclear speech or other speaking difficulties.

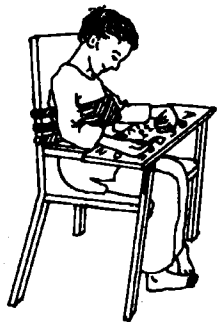


  Although parents find it hard to know exactly what the child wants, they gradually find ways of understanding many of his needs. At first the child cries a lot to show what he wants. Later he may point with his arm, foot or eyes.

- **Intelligence** Some children may seem dull because they are so limp and slow moving. Others move so much and awkwardly they may appear stupid. Their faces twist, or they may drool because of weak face muscles or difficulty in swallowing. This can make an intelligent child appear mentally slow.



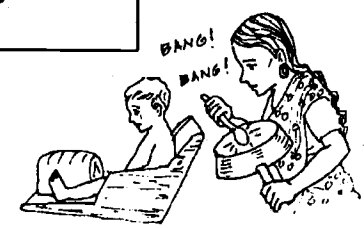
  About half of the children with cerebral palsy are mentally retarded, but this should not be decided too soon. The child needs to be given help and training to show what she is really like. Parents can often tell that she understands more than she can show.



Raju is severely affected with cerebral palsy. Both his legs and hands are affected in such a way that Raju is unable to sit, stand or walk, or even eat or dress himself independently. He is unable to speak and more often than not he cannot join in any physical activity. When outsiders come and meet Raju some feel he is dull and may be even mentally retarded because he does not communicate in ways familiar to them. Others just label him 'mad'. But Raju is none of these things. He composes poems, writes plays and keeps a daily diary. At school and at home Raju sits on a chair specially designed for him. Once in the chair he is able to communicate with the help of a communication board. It is because of Raju's physical appearance that people often mistake him for being dull. They have to learn to understand Raju and other children who are like him.

With help and training some children who have been considered retarded prove to be quite intelligent.

- **Hearing and sight** are sometimes affected. If this problem is not recognized, the family may think that the child lacks intelligence. Observe the child carefully and test him to find out how well he can hear and see. (See p. 544 to 547.)



Even if a child can hear loud banging, he may not hear well enough to understand words.

- **Fits** (epilepsy, seizures, convulsions) occur in some children with cerebral palsy. (See Chapter 29.)

- **Restless behavior** Sudden changes of mood from laughing to crying, fears, fits of anger and other difficult behavior may be present. This may partly be due to the child's frustration of not being able to do what he wants with his body. If there is too much noise and activity the child can become frightened or upset. The brain damage may also affect behavior. These children need a lot of help and patience to overcome their fears and other unusual behavior. (See Chapter 41.)

- **Sense of touch, pain, heat, cold, and body position** are not lost. However, the children may have trouble controlling movements of their bodies and trouble with **balance.** Because of their damaged brains they may have difficulty learning these things. Patient teaching with lots of repetition can help.
- **Abnormal reflexes** Babies have certain 'early reflexes' or automatic body movements that normally go away in the first weeks or months of life. In children with brain damage, they may last much longer. However, these are only important if they affect how the child moves. **'Knee jerk' and other tendon-jump reflexes are usually over-active** (jump higher than normal). If you are not sure, testing for abnormal reflexes may help you tell cerebral palsy from polio. (See p. 42.)

TYPES OF CEREBRAL PALSY

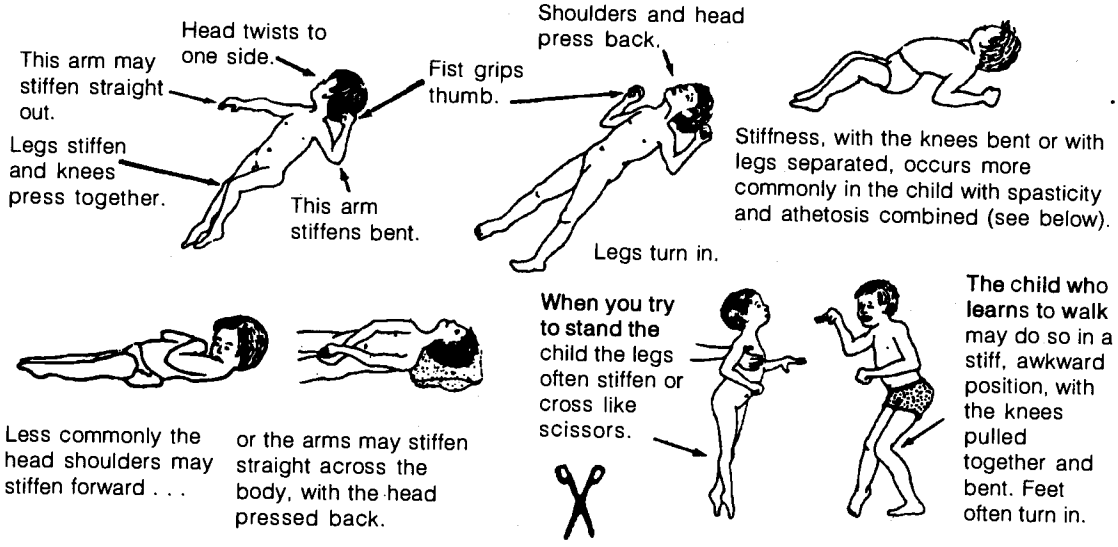
Cerebral palsy is different in every child. Different experts have worked out different ways of describing it. But do not worry about labelling a child's particular type of cerebral palsy. This does not affect his treatment in a big way.

It is helpful, however, to recognize 3 main ways that cerebral palsy can appear. In a particular child, it may appear in one or another of these ways–but usually in some sort of combination.

1. MUSCLE STIFFNESS OR 'SPASTICITY'

The child who is **'spastic'** has **muscle stiffness,** or 'muscle tension'. This causes part of his body to be rigid, or stiff. Movements are slow and awkward. Often the position of the head triggers abnormal positions of the whole body. The stiffness increases when the child is upset or excited, or when his body is in certain positions. **The pattern of stiffness varies greatly from child to child.**

TYPICAL SPASTIC POSITIONS WHEN LYING ON THE BACK:



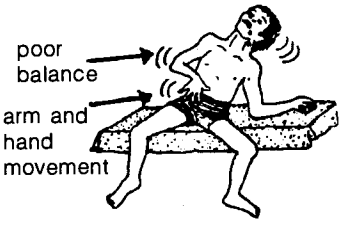
2. UNCONTROLLED MOVEMENTS OR 'ATHETOSIS'

These are slow, wriggly, or sudden quick movements of the child's feet, arms, hands, or face muscles. The arms and legs may seem jumpy and move nervously, or just a hand or the toes may move for no reason. When he moves by choice, body parts move too fast and too far. Spastic movements or positions like those shown above may continually come and go (constantly changing muscle tension). His balance is poor and he falls over easily.

Most children with athetosis have normal intelligence, but if the muscles needed for speech are affected, it may be hard for them to communicate their thoughts and needs.

Typical athetoid arm and hand movements may be as a regular shake or as sudden spasms. Uncontrolled movements are often worse when the child is excited or tries to do something.



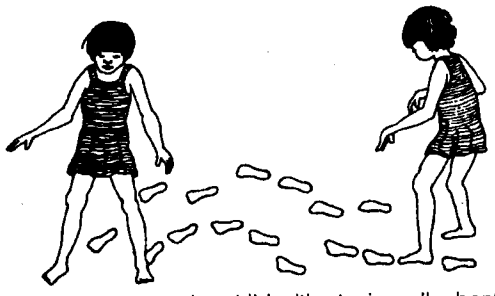


This child has severe athetosis.

3. POOR BALANCE OR 'ATAXIA'

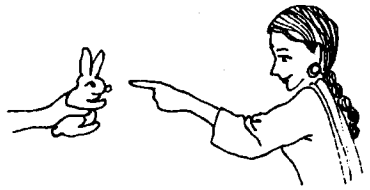
The child who has 'ataxia', or poor balance has difficulty in beginning to sit and stand. She falls often, and has very clumsy use of her hands. All this is normal in small children, but in the child with ataxia it is a bigger problem and lasts longer (sometimes for life).

Because children who have mainly a balance problem often appear more clumsy than disabled, other children are sometimes cruel and make fun of them.



To keep her balance the child with ataxia walks bent forward with feet wide apart. She takes irregular steps like a sailor on a rough sea or someone who is drunk.

TEST FOR ATAXIA :



Hold a finger or a toy in front of the child and ask him to touch it on the first try. The child with ataxia cannot do it.

Many children who have spasticity or athetosis also have problems with balance. This may be a major obstacle in learning to walk. However, much can often be done to help a child improve her balance.

NOTE: Children with any type of cerebral palsy as **babies are often mainly limp or floppy.** Stiffness or uncontrolled movements begin little by little. Or the child may be limp in some positions and stiff in others.

Parts of the body affected

DEPENDING ON WHICH LIMBS ARE INVOLVED, THERE ARE 3 TYPICAL PATTERNS:

ARM AND LEG ON ONE SIDE (HEMIPLEGIC)

arm bent; hand spastic or floppy, often of little use

this side completely or almost normal

She walks on tiptoe or outside of foot on affected side.



BOTH LEGS ONLY (PARAPLEGIC) or with slight involvement of upper limbs. (DIPLEGIC)

upper body usually normal or with very minor signs. Balance of the upper body may be poor

Child may develop contractures of ankles and feet.



BOTH ARMS AND BOTH LEGS (QUADRIPLEGIC)

When he walks, his arms, head, and even his mouth may twist strangely,

Children with all 4 limbs affected often have such severe brain damage that they never are able to walk.

The knees press together

legs and feet turned inward



Although most cerebral palsy children fit one or another of these patterns, check also for minor problems in other parts of the body.

QUESTIONS ABOUT CEREBRAL PALSY

1. What causes it?

In each child with cerebral palsy, the parts of the brain that are damaged are different. The causes are often difficult to find.

- **Causes before birth :**
  - Problems of the mother such as **toxemia of pregnancy** and diabetes.
  - **Infections** of the mother while she is pregnant. These include German measles and shingles (herpes zoster).
  - Differences between the blood of the mother and child **(Rh incompatibility).**
  - **Inherited.** Although there are families with two or more children who have cerebral palsy, the question of inheritance is still debated.
  - **No cause can be found** in about 30% of the children.
- **Causes around the time of birth :**
  - **Lack of oxygen (air)** at birth. The baby does not breathe soon enough and becomes blue and limp. In some areas, misuse of hormones (oxytocics) to speed up birth narrows the blood vessels in the womb so much that the baby does not get enough oxygen. The baby is born blue and limp-with brain damage.
  - **Birth injuries** from difficult births. These are mostly large babies of mothers who are small or very young. The baby's head may be pushed out of shape, blood vessels torn, and the brain damaged. Misuse of forceps also often leads to brain injuries.
  - **Prematurity.** Babies born before 9 months and who weigh under 2 kilos (5 pounds) are much more likely to have cerebral palsy. In rich countries, over half the cases of cerebral palsy happen in babies that are born early.
- **Causes after birth :**
  - **Very high fever** due to infection or dehydration (water loss from diarrhea). It is more common in bottle-fed babies.
  - **Acute Jaundice** just after birth.
  - **Brain infections** (***meningitis, encephalitis***). There are many other causes, including malaria and tuberculosis.
  - **head injuries.**
  - **Lack of oxygen** from drowning, gas poisoning, other causes.
  - **Poisoning** from lead glazes on pottery, pesticides sprayed on crops, and other poisons.
  - **Bleeding or blood clots in the brain,** often from unknown causes.
  - **Brain tumors.** These cause progressive brain damage in which the signs are similar to cerebral palsy but steadily get worse.

2. Is cerebral palsy contagious?

No! It cannot be passed from one child to another.

3. Why are some children more affected than others?

Since cerebral palsy is caused as a result of damage to the brain, the degree of disability will depend on how much of the brain is damaged and where. If a large part of the brain is damaged the child will be more severely affected.

4. Can persons with cerebral palsy marry and have children?

Yes, And the children will not have the condition. (except may be in a very rare type of cerebral palsy.) However, experience shows that most persons with cerebral palsy do not get married because of their multiple handicaps. Those who do get married are often people who are usually totally independent in their day to day activities. Even those who can set up their homes, have very few opportunities to meet and interact with other eligible people.

5. What medical or surgical treatment is there?

Except for drugs to control fits, medicines usually do not help. Although medicines to reduce spasticity are often prescribed, they usually do no good, and may cause problems. Surgery is sometimes useful for correcting severe stubborn contractures. For children whose legs often stiffen or cross like scissors, it may become very difficult to toilet and then clean. Simple surgery can help reduce the scissoring and help make cleaning after toileting easier. **However careful evaluation, may be over 'several sittings' is essential before deciding on surgical procedures.**

Surgery is also performed in order to improve the posture of a child who is already standing or to help the child walk. In a child who cannot balance well enough, surgery usually will not help. Surgery should be considered only if the child has balance in standing. Surgery to weaken or release spastic muscles may sometimes make things worse so extreme caution is required.

6. What can be done?

The damaged parts of the brain cannot be repaired, but often the child can learn to use the undamaged parts to do what she wants to do. It is important for parents to know more or less what to expect.

> **The child with cerebral palsy will become an adult with cerebral palsy. Searching for cures will only bring disappointment. Instead, help the child become an adult who can live with her disability and be as independent as possible.**

Families can do a lot to help these children learn to function better. Generally, **the child who is more intelligent will learn to adapt successfully to her condition.** However, intelligence is not always necessary. In fact, some intelligent children become more easily frustrated and discouraged, so they stop trying. Extra effort is needed to find new and interesting ways to keep them, progressing. **Even severely retarded children can often learn important basic skills.** Only when mental damage is so great that the child does not respond at all to people and things is there little hope for much progress. However, before judging the child who does not respond, be sure to check for deafness or loss of eyesight.



Spastic Society of Northern India Photo : Mukul Kishor

IMPORTANT: Rather than try to treat the symptoms of cerebral palsy, we can do more for the child if we **help her with development of movement, communication, self-care and relationships with others.** Sometimes we can partly correct the symptoms through helping the child develop basic skills.

Family members can learn to play and do daily activities with the child in ways that help her both to function better and to prevent secondary problems such as ***contractures.***

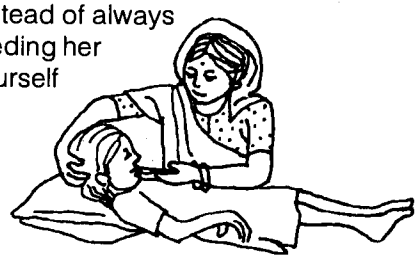
Most important is that the parents (and grandparents!) **learn not to do everything for the child. Help her just enough that she can learn to do more for herself.**



By standing on her knees as she paints a sign, this girl is improving her balance to help her (possibly) stand and walk.

For example, if your child is beginning to hold up her head, and to take things to her mouth,

instead of always feeding her yourself



look for ways to help her begin to feed herself (see p. 401).

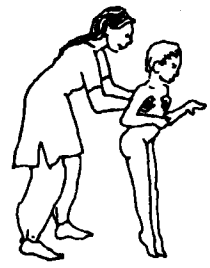


7. Will my child ever be able to walk?

This is often one of the biggest concerns of parents. Walking is important both ***functionally*** and socially. But in terms of the child's needs, other skills may be more important. For the child to lead as happy, independent a life as possible, necessary skills and accomplishments (in order of importance) are:

1. Having confidence in yourself and liking yourself
2. Communication and relationship with others
3. Being able to sit, either supported or unsupported
4. Using hands to perform activities
5. Self-care activities such as eating, dressing, toileting
6. Getting from place to place, with the help of aids
7. (And if possible) walking

We all need to realize that **walking is not the most important skill a child needs** – and it is certainly not the first. Before a child can walk he needs reasonable head control, needs to be able to sit without help, and to be able to keep his balance while standing.



The legs stiffen and the feet go into a rigid *tip toe* position.

The child is *not* almost ready to walk.

A COMMON MISTAKE

When a child with severe – brain damage is held like this, her legs may automatically stiffen and her feet point down – the so-called 'tiptoe reflex'. Because the feet sometimes take jerky 'steps', parents think the child is 'almost ready to walk'. This is not so. The tiptoe reflex must be overcome before the child can begin to learn to walk. Do not hold the child in this position or make her try to walk. It will only strengthen this disabling reaction and lead to contractures in the ankles. Later, if the child is ready to stand, she may not be able to do so because of deformities in her ankles (See p. 359).

Many children with cerebral palsy do learn to walk, although often **much later than normal.** In general, the less severely affected the child is and the earlier she is able to sit without help, the more likely she is to walk. If she can sit without assistance by age 2, her chances for walking may be good-although many other factors are involved. Some children begin to walk at age 7, 10, or even older.

Hemiplegic and diplegic children usually do learn to walk, although some may need crutches, braces, or other aids.

Many severely affected children may never walk. We need to accept this, and aim for other important goals. **Whether or not the child may someday walk, he needs some way to get from place to place.** Here is a true situation that helped us to realize that other things are more important than walking.

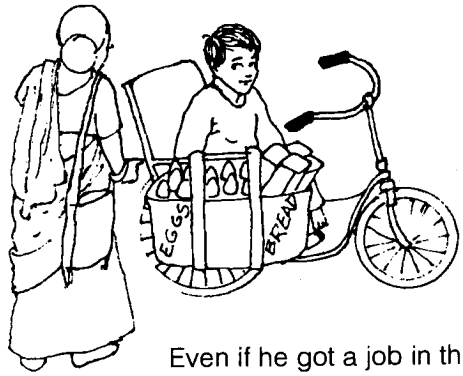


Child standing with body brace and leg braces

Another common mistake

Often parents feel that if their child is straightened out (by wearing a body brace and braces in his legs) he will be able to walk. But such a child is like a log of wood. You can make him stand but not walk.

Ashok lives in a village in Haryana very near the city. Ashok has cerebral palsy.



Ashok walked but with great difficulty. Walking for long distances tired him a great deal. With the result that he did not like to go to places that were far off and felt very sad. Ashok was 17 years old and was very keen to earn and contribute to his house. He wanted to work.

Even if he got a job in the city it was difficult for him to walk there. He could not jump into buses and the buses are erratic in any case. So a solution was found. Ashok was given a tricycle at the rehabilitation centre, which he learnt to ride. Suddenly, a whole new world opened out before Ashok. He began to plan....."I will put some eggs and bread in my tricycle and go and sell them to people at their houses". A door to door service? Who wouldn't want that? Today Ashok cycles and earns money. He also gets a lot of exercise and meets a lot of people.

There are many different ways to help children who cannot walk, or who walk with difficulty, get where they want to go. These include **wheelboards, wagons, wheelchairs, special walkers,** and **hand-pedal tricycles.** Many of these are described in PART 3 of this book (see the Index).

What will happen to my child after me?

This is the greatest worry of most parents. It becomes more intense as the child grows older, heavier and management becomes more difficult. If the child has difficulty communicating, parents worry. "How will she communicate basic things like she wants water or food after I am gone? I can understand the way she communicates, but, will others? I will do everything for her as long as I am alive but later on who will look after her" ?

The later it gets the more difficult it becomes for the child to learn to dress, toilet, eat independently or even to speak. So she remains dependent on others for these everyday tasks. That is why it is best if a trained person can see the child **as early as possible**. She can advise the parents on how to help their child become more and more independent. If the child can learn to do things for herself it becomes easier for her brothers and sisters to look after her when the parents cannot. In some places parent's associations have been formed with the main aim of looking for homes where children with no other support can stay after their parents. Parents have even mooted the idea of building a home for their children with cerebral palsy so that they can stay there after their parents are no longer alive.

How can we help?

First, with the help of parents and family we observe the child carefully to see:

- what the child ***can*** do .
- what he looks like when he moves and when he is in different positions.
- what he ***cannot*** do, and what prevents him from doing it.



A village worker and father examine a child with severe cerebral palsy.

WHAT THE CHILD CAN DO

Can the child:

- lift her head? hold it up? roll over?
- Pull herself along the floor in any way possible? crawl? walk?

  How does the child use her **hands**?
- Can she grasp things and hold on; let go; use both hands together (or only one at a time)?
- Can she use her fingers to pick up small stones or pieces of food?

  How much can the child do for herself?
- Can she feed herself; wash herself; dress herself? Is she 'toilet trained'?

  What can the child do in the home or in the fields to help the family?

After observing and discussing what the child **can do**, we must **expect him to do these things**. If the parents are used to doing almost everything for the child, at first this may be difficult (for both parents and child). But soon it will help the child have more confidence. The parents, also, will be encouraged by seeing what he can do for himself, and they will think less about what he cannot do. Here a grandmother helps her grandchild became more self-reliant:

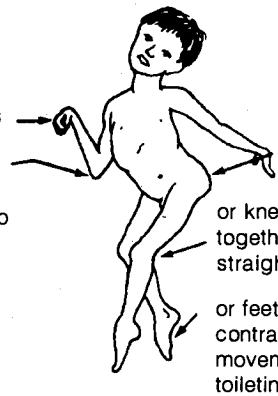


It was difficult for the grandmother not to bring her grandson a cup of water especially when he begged her. But she understood that in the long run it would do him more good to manage for himself. For more ideas about how a family can help a child with cerebral palsy, read the story on pages 5 to 7 and the story of Amit on page 356.

HELPING THE CHILD ACHIEVE BETTER POSITIONS

Due to abnormal pull of muscles, children with cerebral palsy often spend a lot of time in abnormal positions. These abnormal positions of the limbs and body should be avoided as much as possible, or the child can become deformed. For example,

A wrist or elbow that is always bent can lead to contractures (muscle shortening) that make it impossible to straighten the arm or hand.



Hips that are continually bent forward, or to one side,

or knees that are always together, or never completely straightened.

or feet that are always 'tiptoe', can lead to contractures that prevent the normal range of movement. This can make washing dressing, toileting, and moving about much more difficult.

A twisted position can lead to curvature of the *spine* and tilting of the hips

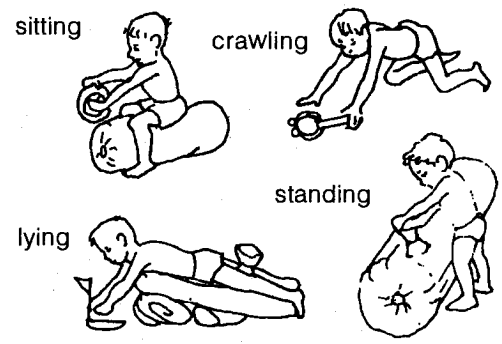


If the head is always turned or bent to one side, in time the neck may become parmanantly twisted.

An arm that is held tightly to the side with in time become difficult to raise away from the side.

Whenever possible the child should be in positions that prevent rather than cause these problems. Whatever the child is doing (lying, sitting, crawling, standing) try to encourage positions so that:

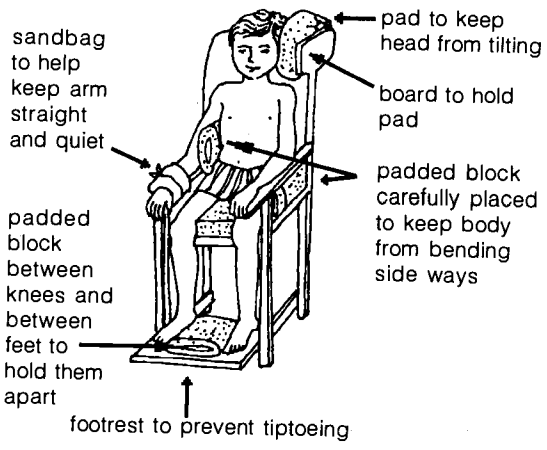
- her head is straight up and down.
- her body is straight (not bent, bowed, or twisted).
- both arms are straight and kept away from the sides.
- both hands are in use, in front of her eyes.
- she bears weight equally on both sides of her body – through both hips, both knees,both feet or both arms.



Encourage positions that the child can manage at her stage of development. Play with her, talk with her, give her interesting things to do in these positions.

Not all children will be able to stay in these positions without some kind of support. Special chairs, tables, wedges, pads, or bags of clean sand may be needed to keep a good position.

For example, the child on the page before this one might need a chair like this.



Note: Remove straps and supports as soon as the child is able to stay in a good position.

> ***WARNING:*** Do not leave a child in any one position for many hours as his body may gradually stiffen into the position. Change his position often. Or better, encourage him to change it. If he can change his own position effectively, then chairs, seats, and other aids must not prevent him from moving.
>
> AIDS SHOULD RESTRICT A CHILD'S MOVEMENT AS LITTLE AS POSSIBLE.

When the child with cerebral palsy moves she may do so in a very strange or abnormal way. To some extent this should be allowed, as long as the child is able to do things as best she can. But also show the child other ways to move in order to correct some of the abnormal positions that she repeats again and again. For example,

If her arm repeatedly bends up, encourage her to reach out and hold objects



Or she may need a post to hold on to

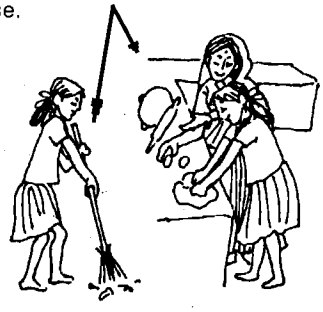




If she bends backward a lot,



she needs actions that bend her head, body, and shoulders forward, like these.



Corrective actions and positions can be found while working in the fields, in the home, or while playing with brothers and sisters. Here are some more suggestions for corrective positions (from physical therapists Nancy Finnie and Sophie Levitt).

Lying and sleeping

Try to find ways for the child to be in positions that correct or are opposite to his abnormal ones.



For example, if the baby's knees usually press together or his legs cross like scissors.



The baby's legs can be held apart by putting a small pillow using many thicknesses of diapers *(nappies)* like this, or just many layers of clean cloth.



Or by pinning her legs like this.

If the child's body often arches backward.try positioning him to lie and play on his side.



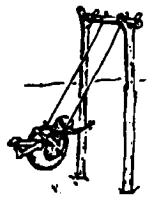


Look for ways to break the spasticity by bending him forward in a hammock. This hammock was made by tying the two ends of a saree to the two trees.

Or over a sack of grain or big barrel etc.



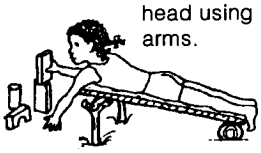
Or in a car tyre swing



If the child does not have enough control to reach out in this position.



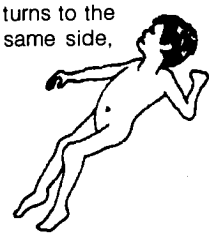
help position him so he can lift his head using his arms.





hole in the ground to prevent tiptoeing. You can roll up a thick mattress in a way that one edge is bigger than the other.

If the child's head always turns to the same side,



do not have him lie so that he turns his head to that side to see.



WRONG

Instead, have him lie so that he has to turn his head to the other side to see the action.



RIGHT

For more suggestions on head control, see p. 372.

Rolling and twisting

A child with cerebral palsy is often very stiff when it comes to twisting or rotating the main part of her body. However, such twisting is necessary for learning to walk. Rolling also helps develop body twisting.

If the child is very stiff, first help her loosen up by swinging her legs back and forth.

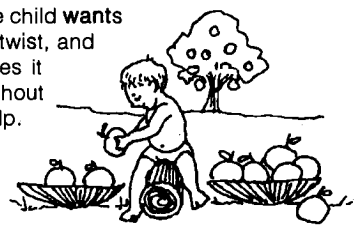


Then help her learn to twist her body and roll.





Figure out games so that the child **wants** to twist, and does it without help.



For more ideas to develop twisting and rolling, see p. 374.

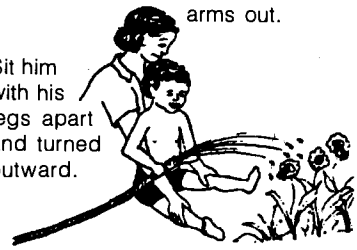
Sitting

The way that you help position a child for sitting also depends on the type of abnormal body positions he has. For example,

If his legs push together and turn in, and if his shoulders press down and his arms turn in.



Sit him with his legs apart and turned outward.



Also lift his shoulders up and turn his arms out.

Look for simple ways to help him stay and play in the improved position without your help. This child sits in a large vessel normally used for cooking.





Sitting with the legs in a ring helps turn hips outward. The chullah used for cooking in many village homes was useful for her.



For the child with spasticity who has trouble sitting, you can control his legs like this. This leaves your hands free to help him control and use his arms and hands. Help the child feel and grasp parts of his face.



Sit the child on your belly with his legs spread and feet flat. Give support with your knees as needed. As he begins to reach for his face, help his shoulders, arms, and hands take more natural positions. Make a game out of touching or holding parts of his face MAKE IT FUN!



As the child develops, encourage her to put her arms and body in more normal positions through play and *imitation*



Children who have trouble with balance (from cerebral palsy, polio, or other disability) often sit with their legs in a W in order not to fall over.





Sitting in a "W" should usually be discouraged because it can increase contractures and loosen or damage hips and knees. However, if deformities have set in and if it is the only way a child can sit and use her hands, it should be allowed. But for a very young child we must look for alternatives.



The traditional cross legged position is also not a good position for children with cerebral palsy. The hips, knees and feet are bent when a child sits this way. However, if the child does not have any deformities in the knees or feet, she can use this position to do some activities since it does provide a broad base and more stability.

The pot or log keeps the knees apart. The holes for heels help too.

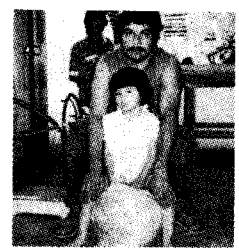


If the child's legs stay apart his bottom sticks out and his shoulders are pulled back.



first sit him with his body bent forward and his legs together. Then bend his shoulders forward and turn





A sack of grain provides a roll to hold this child's legs apart. her father pushes down on her knees. This helps her to hold her feet flat and sit up straighter. (PROJIMO)

Look for ways that the child will sit and play in the improved position without help



Play with her at a table. Sit across from her to have her reach forward for toys with both hands.

Be sure her feet are on a flat surface.

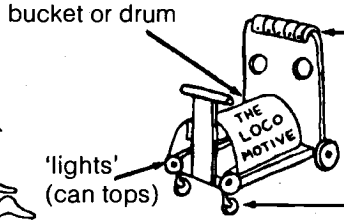
For ideas on special seats and sitting positions to prevent 'knock-knee' contractures, see below. Other ideas on special seats for children with cerebral palsy are on pages 378, 697, 733 to 738, 749 and 752.

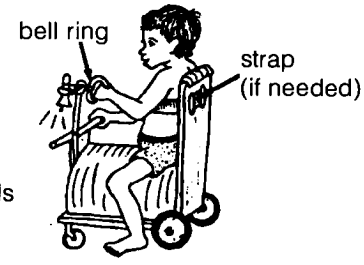
Moving about

Because children with cerebral palsy are usually delayed in walking, they need other ways to get from place to place. The methods used will depend on both the needs and abilities of the child – also the resources, skills, and imagination of family, friends, and local craftspersons.

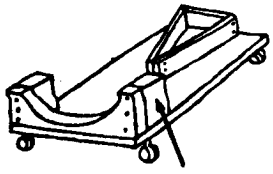
Aids for ways to get from place to place should provide corrective positions. The following examples are all designed to help prevent 'knock-knee' contractures. They also provide other types of corrective positioning.





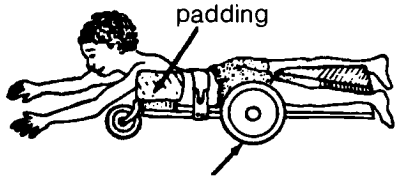


Wheelboards



Pad or put a pillow over this support (Some children will not need this support)

Adapting wheelboards for travel on rough surfaces'



By placing large wheels near the middle if the smaller front caster gets stuck, the child can lift with his arms and go on. Or if a fixed front wheel is used, he can lift it off the ground to make turns. For dirt or bamboo floors, larger wheels will be needed.

For other wheelboard designs, see p. 746.

Some children will need wheelchairs. For **wheelchair designs, see Chapters 65, 66 and 67.**



For special cushions, to help hold a child's hips back and her knees apart, **see p. 735.**

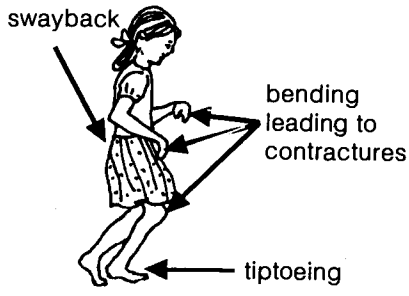
Standing

Many children with cerebral palsy stand and walk in strange positions. A child's unsure balance often increases the uncontrolled tightening of certain muscles and makes balance even more difficult.

As a result the child stands in an awkward position that can lead to deformities and contractures.

When you help the child keep her balance, she is less tense and can stand straighter.

Look for ways to provide similar assistance during play and other activities





Here a cart provides easier balance and keeps the arms straight.





Maiguelito began to walk at age 8 – first on parallel bars.



Soon he learned to use crutches. Here he races another child who is learning to walk



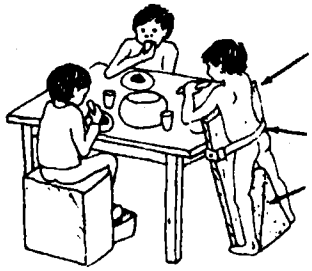
And now he can walk alone.

Two sticks can help the child once she develops some standing balance. At first you can hold the tops of the sticks. But let go as soon as possible.

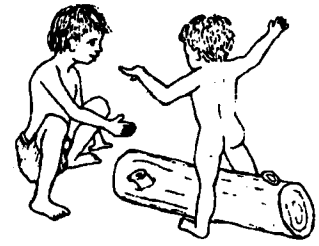
CAUTION: Be sure sticks are taller than child so that she will not injure herself if she falls.



The child who cannot yet stand alone can be placed in a standing frame for an hour or 2 each day.







Even for the child who may never stand alone or walk, standing in a frame helps prevent deformities. It also helps the leg bones grow and stay strong. Start at about the age normal children begin to stand – around one year old.

For ideas on 'standing frames' see p. 698 and 699.

Hand use

Try to find ways that the child can play or do things using her hands while she is in the corrective positions of sitting, standing or lying.

Encourage her to touch, feel, and handle as many different shapes and surfaces as possible: things that are big, small, hot, cold, sticky, smooth, prickly, hard, soft, thin and thick.

This girl in the rehabilitation centre of the Khao-i-dang refugee camp in Thailand develops hand controls by sliding coloured rings on a pole.





A boy with cerebral palsy stamps wrapping paper with beautiful designs. Later these will be sold in shops.
Photo : Spastic Society of Northern India

For more ideas of developing use of the hands, see p. 375.

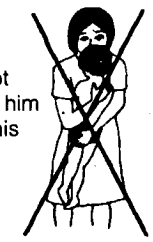
CORRECTIVE CARRYING POSITIONS

As in other activities, try to carry a child in positions that work to correct abnormal positions.

If the child usually lies with arms bent and legs straight.



do not carry him like this



Carry him in ways that straighten his arms and bend his knees and hips.



The traditional way of carrying the child is most beneficial for such a child.



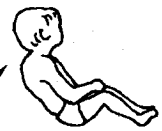
As the child gains more control, you can carry him with less support.



The child with severe spasticity who tends to straighten and arch backwards can be carried like this.



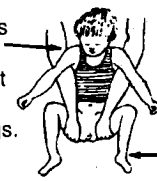
The child with spasticity who is usually curled up,



can be carried like this. Do not carry this child in the traditional way, across the hips.



Pushing shoulders up helps relax tight spasms of the legs.



holding the child by his inner thighs helps turn legs out as they separate

For play, you can swing the child in the air in this position.



While working, you can carry the baby with legs spread across your hips or back as is the custom in many places.

The Spastic of Northern India has specially made buggys to transport older children with cerebral palsy.

For other good carrying positions, see p. 373.

So far we have discussed ways in which a child can be helped to get into corrective positions and actions. Here is a true story of how a mother used things available in the local environment to do this.

A few days after she was born, Shashibala got acute jaundice. Later, it was discovered that she found it very difficult to move her left arm and her left leg. She was also mentally retarded and could not see very well.

Shashibala is now nearly 6 years old. She lives in Tigaon a village in Haryana, with her parents, grandparents and a large number of uncles, aunts and cousins.

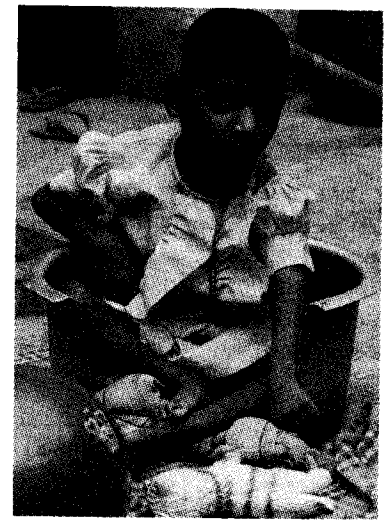
As she grew older her mother's major worry was that Shashibala could not sit on her own. She would always fall onto her left side. As a result she lay the whole day and found it difficult to sleep in the nights.

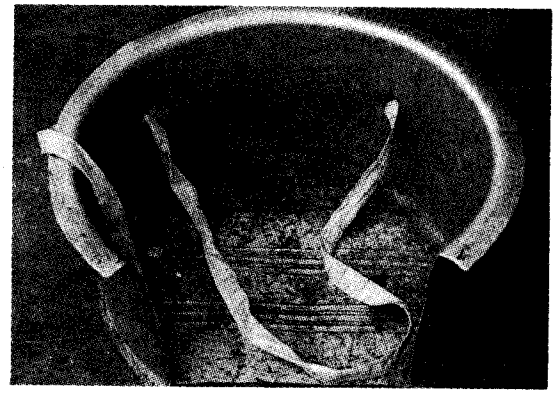
Phoolwati, the village rehabilitation worker from the Spastics Society tried propping Shashibala against a corner of the house so that she would be supported, but Shashibala hated it. She hated being all alone in a corner when everybody else was outside in the courtyard.

One day, her mother was working and Shashibala was as usual lying next to her on a mat. Suddenly, the mother's eyes fell on a large utensil *(patila)* used for cooking the family's meals. She picked up Shashibala and put her inside the utensil in a cross legged position. It was a perfect fit! When Phoolwati came the next day and saw Shashibala sitting in the utensil she couldn't believe her eyes. The sides of the utensil prevented Shashibala from falling. Being light, she could easily be carried around to different places in the utensil. And now she could at least be part of the activities that were going on in the house.

Days passed and it became important that Shashibala stretch her legs out and sit so that she would not get contractures. So Phoolwati took the utensil to a nearby shop and had one side of the utensil cut off. She then got two holes made at the back of the utensil through which a long piece of cloth was inserted. This was then used as a belt for Shashibala. Whenever she sat in her utensil chair Shashibala would sit with both her legs stretched out in front.







Meanwhile Phoolwati told Shashibala's mother about how Umed's grandfather had just used the chullah in their house as a corner chair for him. The Chullah with its high sides could be used effectively to give support to a child who was just learning to sit. Shashibala's mother was thrilled. She asked her husband to make another chullah in the courtyard so that their daughter was now never short of a chair!



Soon the time came for Shashibala to experience standing. But when she stood, her left leg bent at the knee and she could not touch her toes to the ground. Shashibala was then given a splint for her leg. Phoolwati and Shashibala's mother invented once again. They sewed up old pieces of cloth in such a way that they could go around Shashibala's legs, padded it a little, and inserted 3 straight sticks at 3 different points, to make a splint. The cloth splint was then tied around Shashibala's left leg to keep it straight. Now Shashibala could even put her whole foot on the ground. So Shashibala got to sit and stand with the help of aids that were made from her own environment.



Photo : Avijit Kishore

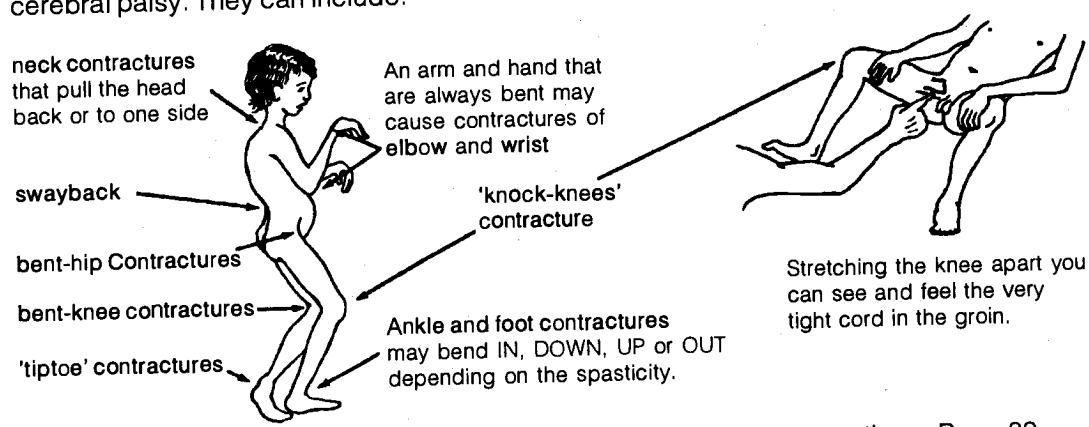
CONTRACTURES IN CEREBRAL PALSY

Abnormal muscle tightness often leads to contractures (muscle shortening and reduced motion of joints, see Chapter 8). In time, the muscles that keep a limb bent become shortened so that the limb cannot straighten even when the muscles relax. But with care, contractures can often be prevented.

Without care to prevent it:

SPASTICITY	leads to	CONTRACTURES
(Uncontrolled tightening of muscles)	→	(Fixed shortening of muscles)

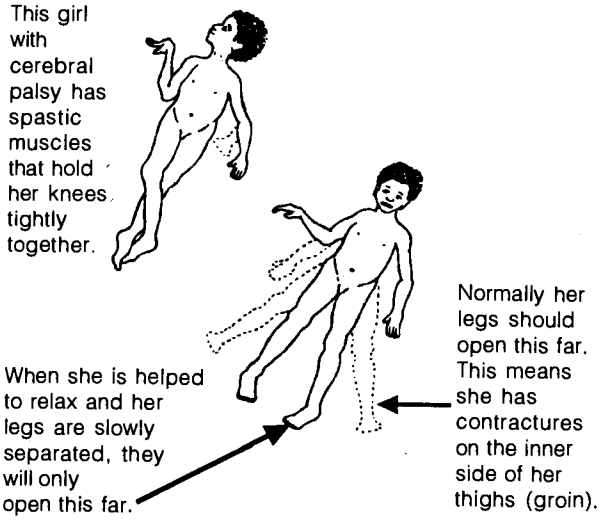
The **typical contractures of cerebral palsy** are similar to the abnormal positions of cerebral palsy. They can include:



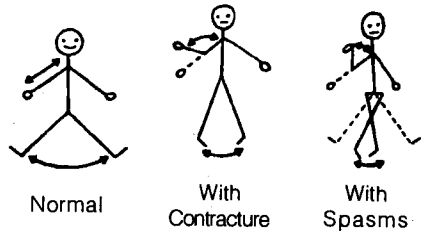
Chapter 8 discusses contractures, and ways to prevent and correct them. Page 89

Spasticity and contractures combined

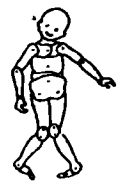
Decreased range of motion may be caused by spasticity and partly by contractures. Check to see if contractures are also forming, and if so, how much.



One way to record spasticity and contractures:



You can use a flexikin to record the positions (See p. 45.)



PREVENTING CONTRACTURES

In cerebral palsy, it is important that steps to prevent contractures be included in activities that help the total developments of the child. Many of the **corrective positions** we have already suggested for activities such as lying, sitting, standing, and moving about are helpful in preventing contractures. When **there are signs of developing contractures, give even more time and care to corrective positions.**

Range-of-motion exercises

Although the reasons contractures form in cerebral palsy and polio are different, many of the stretching and holding exercises discussed in Chapter 43. "Range-of-Motion and Other Exercise," will be helpful. However in cerebral palsy, take care to **do exercises in ways that do not increase spasticity, but help to relax the spastic muscles.**

RELAXING SPASTIC MUSCLES

To help relax spastic muscles, before beginning range-of-motion exercises try the following to see what works best for your child: But before that, make sure that your child is lying, sitting or standing in a corrective position with enough support.

1. Apply warm soaks (see p. 152) to spastic muscles or have the child sit or lie in warm water.



2. Slowly twist or help the child to twist his body from side to side. This reduces spasticity throughout the body, and is a good first stretching exercise. Make it into a game (See p. 374.)



3. Shaking the bent and tense part of the body also helps relax spastic muscles. For example, if the elbow of the child is bent, hold the elbow from below and gently shake it.

CAUTION:

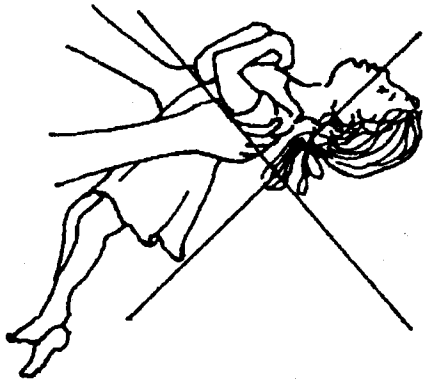
ABOUT MASSAGE

In some countries, people and even therapists use massage, or rubbing, to try to relax spastic muscles. Although massage often helps relax muscle spasms, cramps, or tight muscles from other causes. In spasticity, massage usually increases the muscle tightness. As a general rule. DO NOT MASSAGE SPASTIC MUSCLES

Pulling or pushing directly against spastic muscles causes them, to tighten more. To correct abnormal positions, sometimes you can use 'tricks' to release or 'break' the muscle spasms.

Muscle tension in any part of the body is affected by the position of the head and body. Spasms that straighten the legs and pull the knees together can be partly relaxed by bending the head and back forward.

Do not pick up the child like this. Her head will bend back and her while body and legs stiffen more.



WRONG

If you roll her a little to one side, it will be easier to bend her head and back forward. This relaxes her hips and legs so that they also bend.



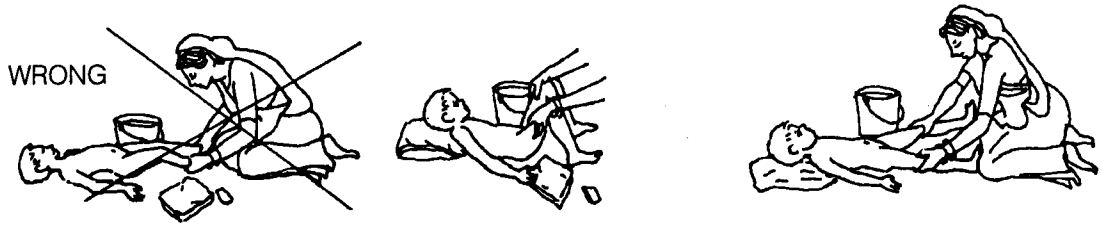
RIGHT

Whatever you do with the child, look for ways that will help relax and stretch the tight muscles. Here are some examples.

Ameena's body stiffens backward, while her knees straighten stiffly and press together.
To wash between her legs, *do not* try to pull her legs apart at the ankles. This will make her legs pull together more tightly.

Instead, put something under her head and shoulders to bend them forward. This helps to relax the stiffness in her whole body.
Then bend the legs and slowly separate them. If you hold them above the knees, they will open more easily.

Washing will be easier with her knees bent. After washing her (with warm water, if possible) you can help stretch the tight muscles. Slowly open her legs as wide as they will go, and then gradually straighten her knees.

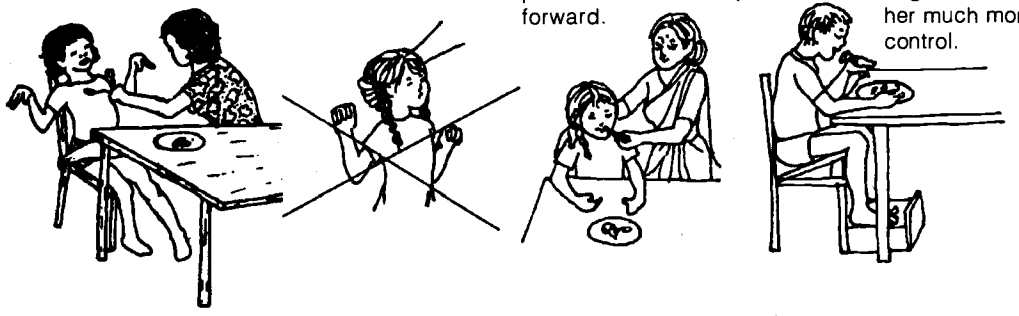


When you try to feed the child, if her head and shoulders stiffen backward

do not try to pull her head forward. It will push back more.

You may find that her head relaxes more if you put your arm across the back of her neck and push her shoulders forward.

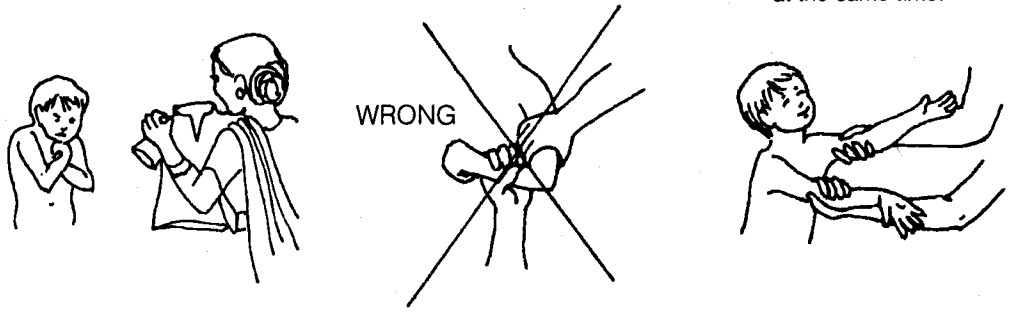
Or, you may find that raising the front of the chair seat keeps her hips bent, relaxes her in general, and gives her much more control.



When you want to help your child dress, if her arms press against her chest

do not try to pull them straight. They will stiffen more.

Try holding her arms above her elbows and gently turning her arms out and straighten them at the same time.



Note: **These suggestions will work for some children but not for others. Keep trying different ways until you find what works best.**

DEVELOPING EARLY SKILLS

Most children with cerebral palsy develop basic skills and abilities more slowly than other children. This is partly because of their difficulty with balance and movement. Also, in some children, mental slowness or problems with seeing or hearing make learning more difficult. Because slow development occurs with many different disabilities, we discuss activities for child development in a separate section of this book.

In this chapter, therefore, we give only a few suggestions for assisting a child with child with cerebral palsy to learn new skills.

> *VERY IMPORTANT:*
>
> To understand better how to help a child with cerebral palsy develop early skills, **you also need to read other chapters.** Chapters 35 and 36 are about **helping the child whose mind and/or body are slow to develop.** Chapter 37 to 42 discuss ways of **helping children develop and become more self-reliant.**
>
> Although Chapters 35 to 42 are writen to help any children who are slow to develop, many suggestions are included for the specific needs of the child with cerebral palsy. These are marked with (CP) in the margin.

To help a child develop new skills, first observe all the things that she can and cannot do. Like a normal baby who progresses stage by stage in a certain order, the child with cerebral palsy must do the same. Charts showing the normal 'developmental milestones' are on pages 360 and 361. You can use them to help decide the next steps or skills that the child may be ready to learn.

Help the child advance slowly, at her own speed, in small steps. If we try to go too fast because of her age, she can became discouraged by failure. Also, her progress can be held back. This happens when we stand a child and try to make him walk before he is ready. (See p. 359.)

> **Move ahead at a speed that fits your child- not too fast and not too slow.**

To help a child with cerebral palsy develop skills takes a lot of time, energy, patience and love. The whole family needs to help, and also, if possible, others in the community. (See Chapter 33.)

Remember that **positioning is very important.** When the child has been helped to lie, sit, and stand in ways that give him better positions and control, he will start learning to do things he could not do before.

Good balance is one of the most important goals for the development of the child with cerebral palsy. It is important to help a child improve her balance from as young an age as possible. At each stage of the child's development – lying,sitting, creeping, standing, and walking-better balance is needed to progress to the next stage.

Helping improve balance

Detailed suggestions of activities to improve balance are included in Chapter 36, "Early Stimulation Activities," especially pages 376 to 382. Here, we give you a brief look at some of the basic suggestions explained in more detail in that chapter.

TESTING A CHILD'S BALANCE

POOR BALANCE



If when you sit a child over 10 months old, she falls stiffly to one side with no effort to 'catch' herself, her balance is poor.

BETTER BALANCE



If she can balance using her arms when you gently push her,her balance is fair.

GOOD BALANCE



If she can do it by bending her body, without using her arms, her balance is good.

When lying

Encourage the child to shift weight from one arm to the other by reaching for objects,

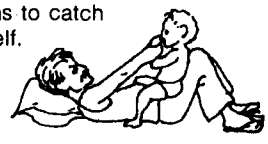


reaching forward,

and reaching sideways.



Lie him on your body and tip a little from side to side so that he begins to catch himself.



When sitting

Let her start to fall so that she begins to catch herself.



Sit her across your knees. Raise one knee so she has to balance.



Start with hands high.



Then lower your hands.

As the child improves,use a tilting board.



Encourage the child to twist and reach the side.



Use as little sitting support as needed. Often low back support is enough for a child who straightens stiffly

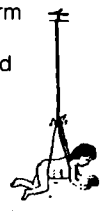


For creeping and crawling

Note: Some children advance to standing without ever crawling.

Shift weight from one arm to the other. Provide support as needed, and gradually take it away.





Shift weight from one leg to the other.



Play trying to balance on a tipping surface.



Crawling forward, sideways, and backward.



crawling scooter



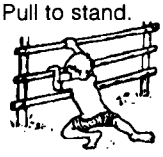
For standing and walking

Stand and balance on knees.



CAUTION: Not for a child with bent-knee spasticity.

Pull to stand.



(Often the child will stand better when he pulls himself up than when someone helps him.)

Stand while holding on, and reaching.



Help with standing and then walking.



Have the child practice stepping forward, backward, and sideways.

Give less and less support while he walks with only a 'safety-belt' - and then alone.





Whenever possible, **turn these activities into games. Talk to the child** a lot while you do them to help develop language skills at the same time (see p. 383).

Skills for daily living and self care

A child with cerebral palsy will get abilities later than other children-but **she will get them!** Of course, the child may not achieve everything, and may not always walk. But **make sure the child achieves what she can in each important area of development:**

The child will often need a lot of help with **language and communication skills.** Develop these skills in whatever way seems possible: using words, gestures, pointing (with hand, foot, head, or eyes), or with communication boards. (See Chapter 31 and p. 702.)



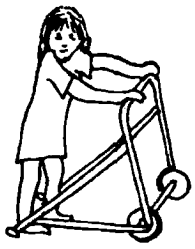


Help the child become as independent as possible in **eating, dressing, washing, toileting,** and, if necessary, use wheelboards, wheelchairs, pedal; tricycles, walkers, crutches, or other aids. (See Chapter 64,65, 66 and 67.) Keep experimenting until you find what works best.

For example, this girl, with poor body and hip control, tends to 'fall through' the space between her arms when the handgrips on the walker are upright.



She does much better on a higher walker with a handgrip that turns from one side to the other

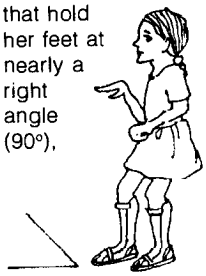


Often leg braces *do not* help a child with cerebral palsy walk better. But sometimes they do. When in doubt, try a low-cost brace first, to look for possible problems. For example:

Ramani walks in a very crouched position.



She may be helped by below-knee braces that hold her feet at nearly a right angle (90°),



or by above-knee braces that keep her knees almost straight . . .

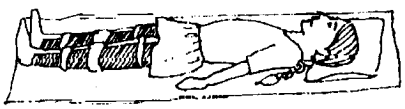


But it is possible that the below-knee braces will throw her badly off balance.



and that the above-knee braces will make balancing even harder

You will need to experiment!



Even if braces for walking do not work. Ramani may be helped to walk straighter by using 'night splints' to hold her knees straight and prevent contractures. (See p. 660.)

IMPORTANT: Practice in learning skills should take place with family and friends so that the child develops skills in relating to others. However, the **child will also need time to practice her skills alone** and with the person who is mainly responsible to treating or teaching her.

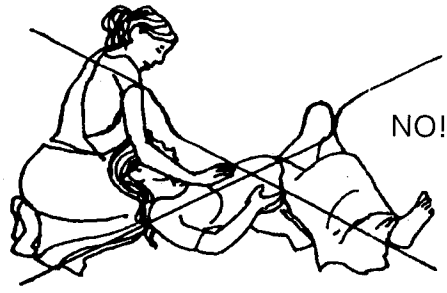
> ***CAUTION:*** Many suggestions for developing basic skills are discussed in Chapter 35, "Child Development and Developmental Delay," and Chapter 37 through 40 on developing skills for self-care. However, **for the child with cerebral palsy, some of these activities will need to be done differently** to help reduce and not increase muscle spasms. **If any activity increases spasticity, try it differently until you find a way that reduces muscles tension and improves position.**

PREVENTION

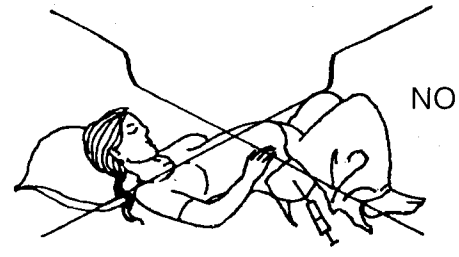
With these precautions, children will be less likely to have cerebral palsy:

- **Good nutrition of the mother,** both before and during pregnancy, reduces the chance of premature birth - and of cerebral palsy.
- If possible, girls should **avoid pregnancy until full grown** (16 or 17 years old).
- **Avoid unnecessary medicines during pregnancy.**
- Try to **avoid** getting near persons with **German measles** during pregnancy. Or get vaccinated against German measles before becoming pregnant.
- Go for regular **health check-ups during pregnancy** (prenatal care). If there are any signs that giving birth may be difficult, try to arrange for a skilled midwife or doctor to attend the birth – if possible, in a hospital. (See the list of "Signs of Special Risk," ***Where There Is No Doctor*, p. 390.)**
- During labor, do not let the midwife try to speed things up by,

pushing forcefully against the womb.



or by using injections or hormones (oxytocin, pitutrin, etc.) before the child is born.



- Be familiar with, and be sure your midwife is familiar with, all the precautions and **emergency measures** of childbirth. Learn what to do if the baby is born blue and limp and does not breathe right away, or has the cord wrapped around the neck. (See ***Where There Is No Doctor*, p. 395.)**
- **Breast feed** the baby (breast milk helps **prevent and fight** infections, and make sure the baby gets enough to eat. (See ***Where There Is No Doctor*,** p. 164–167 and 406.)
- **Vaccinate** the baby (especially for measles).

- When the baby has a **fever,**

uncover him completely.



If the fever is high, wet the child and fan him until he is cooler.

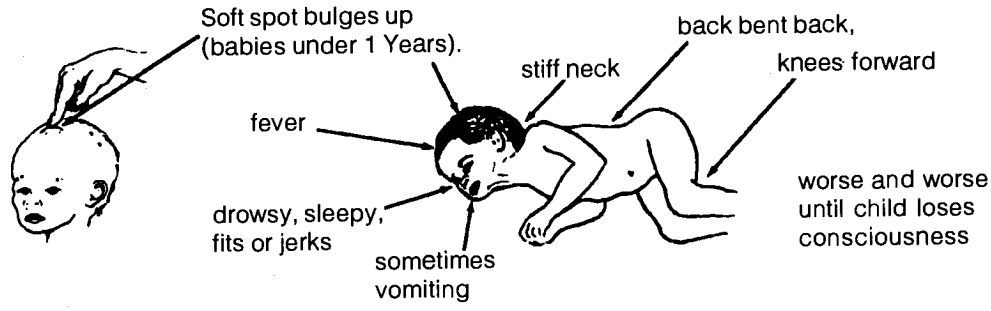
Never wrap the baby up in clothing or blankets



This can make the fever worse and cause fits or permanent brain damage.

Be sure the child with fever drinks a lot of liquids, and follow the other instructions pages 109 to 110 of ***Where There Is No Doctor.***

- Know the signs of **meningitis** and get (or begin) treatment quickly.

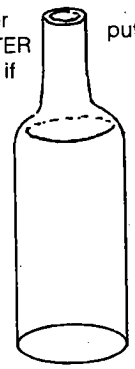


- When your baby has **diarrhea,** prepare Rehydration Drink and give it to him every few minutes to prevent or correct dehydration. See ***Where There Is No Doctor,*** p. 233 to 242.

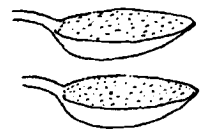
Preventing dehydration helps prevent fits and brain damage (cerebral palsy).

REHYDRATION DRINK – TO PREVENT AND TREAT DEHYDRATION

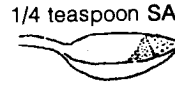
In 1 liter of WATER (better if boiled, but do not lose time)



put 2 level tablespoons of SUGAR or honey



and 1/4 teaspoon SALT



and 1/4 teaspoon **BAKING SODA** (bicarbonate of soda).



CAUTION: Before giving the Drink taste it and be sure it is no more salty than tears.

If you do not have soda, use another 1/4 teaspoon salt.

If available, add half a cup of orange juice or coconut water or a little mashed ripe banana to the Drink.

OTHER PARTS OF THIS BOOK WITH INFORMATION CONCERNING CEREBRAL PALSY

Cerebral palsy is a complex disability that involves many problems and needs. Therefore much of the basic information you will need is in other chapters. It is essential that you read Chapters 4, 8, 33, 44 and 63 to 67.

Throughout the book, important information about cerebral palsy has been marked with a (CP) in the margin. Many references to cerebral palsy are also included in the INDEX.

CHAPTER **10**

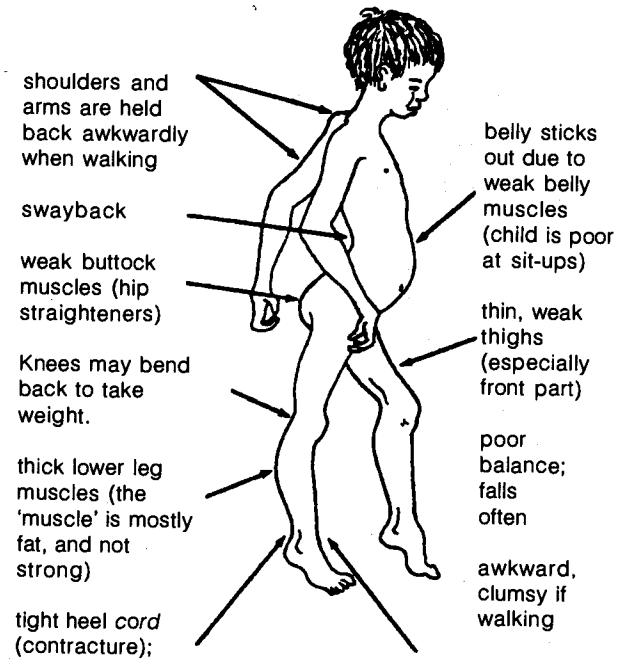
Muscular Dystrophy

Gradual, Progressive Muscle Loss

Muscular dystrophy is a condition in which ***muscles,*** month by month and year by year, get weaker and weaker. Because the ***disability*** gradually gets worse, we say it is 'progressive'.

HOW TO RECOGNIZE IF MUSCLE WEAKNESS IS CAUSED BY MUSCULAR DYSTROPHY

- Mostly affects boys (rarely girls).
- Often brothers or male relatives have same problem.
- First signs appear around ages 3 to 5: the child may seem awkward or clumsy, or he begins to walk 'tiptoe' because he cannot put his feet flat. Runs strangely. Falls often.
- Problem gets steadily worse over the next several years.
- Muscle weakness first affects feet, fronts of thighs, hips, belly, shoulders, and elbows. Later, it affects hands, face, and neck muscles.
- Most children become unable to walk by age 10.
- May develop a severe curve of the spine.
- Heart and breathing muscles also get weak. Child usually dies before age 20 from heart failure or pneumonia.

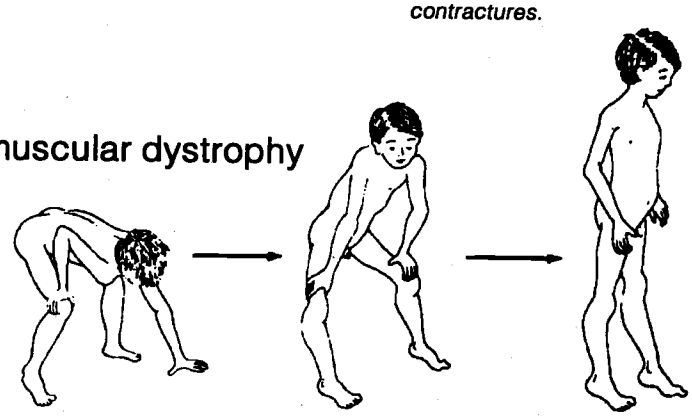


Weak muscles in front of leg cause 'foot drop' and tiptoe ***contractures.***

Early common sign of muscular dystrophy

- To get up from the ground, the child 'walks up' his thighs with his hands.

  This is mainly because of weak thigh muscles.



QUESTIONS ABOUT MUSCULAR DYSTROPHY

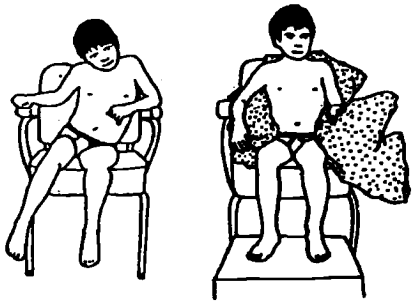
How common is it? It is not very common. ***rehabilitation*** centers may see one child with muscular dystrophy for every 30 or 40 with cerebral palsy or polio.

What causes it? Nobody knows. But in 2 out of 3 families with muscular dystrophy, there is a history of it among male relatives of the mother. Though the parents are usually normal, the mother carries the 'gene' that produces dystrophy in her sons. Her daughters will develop normally, but they may have sons with muscular dystrophy.

What treatment is there? None. No medicines help. Special therapy or exercises will not stop the weakness from increasing. Surgery to release tiptoe contractures is at best of temporary benefit.

The family can, however, do much to help the child make the best of his life and adapt to his limitations as they progress.

Also, activities, exercise and braces to prevent contractures may help the child to keep walking longer (see p. 125). If the child sits in a bad position, pillows or supports to help him sit straighter can help prevent deformities.



Is the child's mind affected? About half of these children are somewhat mentally retarded (slow learners); some are very intelligent.

What can be done? The family can do many things to help the child live more fully and happily. The child should remain active and continue normal activities for as long as possible. Play with other children is important. So are learning and exploring. The child should go to school. Encourage other children to help him with learning and play. The teacher should realize that some–but not all–children with dystrophy learn a little more slowly than normal. Try to include the child in as many family and community activities as possible.

The steadily increasing weakness and the lack of effective treatment will be hard for both the family and child to accept. Friendly assistance, advice, and encouragement from health workers and friends can be a big help. Help the family to look at the situation honestly, and to do their best.

The goal of the family is to help the child be as active and happy as possible, and to adjust to his increasing limitations.



A boy with muscular dystrophy paints the top of his wheelchair table. Although he cannot lift his arm without help, a simple 'arm rocker' made of foam plastic lets him move it in all directions. It also allows him to feed himself. (See p. 403)

Helping the child to keep walking for as long as possible

Exercise. To keep as strong as possible and prevent contractures, probably the best therapy, at least at first, is to stay active, to walk, run, and play. While range-of-motion and stretching exercises may help (see Chapter 43), it is even better to involve the child in games, work, and other activities that keep his joints flexible. Even though he is slow and awkward, encourage him to take part. Feeling sorry for him and just letting him sit is the worst thing you can do.

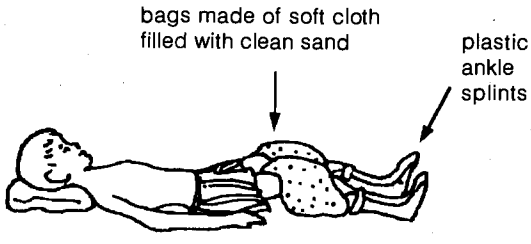


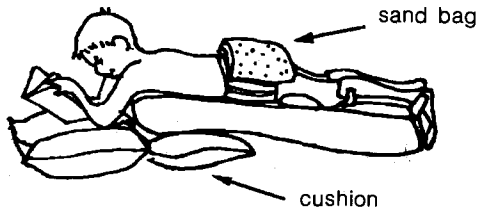
Walking uphill and hillside farm work help prevent tiptoe contractures of the ankles.

Braces. Long-leg braces should not be used until absolutely necessary, as they will let the child's legs grow weaker faster. Sometimes lightweight plastic ankle splints, worn day and night, will help delay ankle contractures and keep him walking better. (See Chapter 59.)



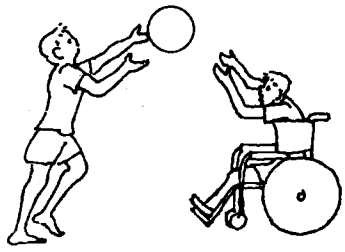
If **contractures of the knees and hips** begin to develop, try resting or sleeping with 'sand bags' to press down the legs and help straighten them.





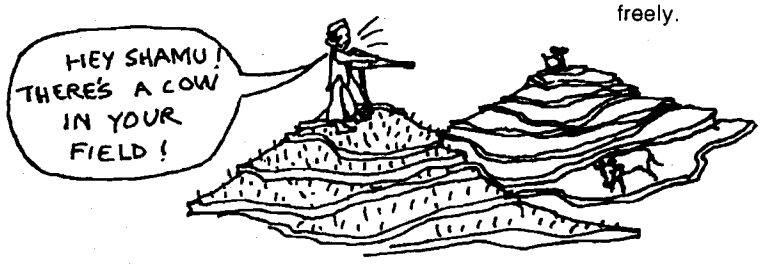
CAUTION: Balance your efforts to provide therapy or surgery against the need of the child (and his family) to lead as full, happy, and normal a life as possible. His weakness will increase and his life will be short regardless of all efforts. The goal of all care for the child with muscular dystrophy should be to help him get the most out of living *NOW*. The temporary benefits of surgery should be weighed against the pain and hardships it would involve.

Other aids. The child will reach a point where he needs to use **crutches**. Later, (often by age 10) he will not be able to walk. Do not force him when it becomes too hard. Instead, try to obtain or make a **wheelchair**. (See Chapter 65 to 67.) At first, the child may be able to roll it himself. But as his weakness progresses, he may need to be pushed.



A wide cloth or canvas strap across his belly and chest may allow the child to play, to lean forward, and to use his arms more freely.

Breathing deeply is important, especially when the muscles that move the lungs begin to weaken. Encourage the child to sing loudly, to shout, to blow whistles, and to blow up balloons.



Shouting and climbing are both good exercise for the lungs

Other problems

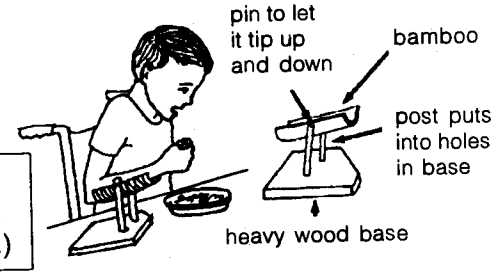
- **Getting fat** is a common problem in children with dystrophy. The child needs to eat a healthy balanced diet. But take care not to let him eat too much–especially sweet things. Extra body weight will make walking, breathing, and other activities more difficult for his weakening body, and will make it harder for family members to lift him.

- **Constipation (hard, difficult stools)** may become a problem. Drinking lots of liquid helps. So does eating fruits and vegetables, and foods with lots of fiber (see p. 250).

- **Spinal curve** can become severe (see picture of Tito drawing, below). A corset or body brace may help hold the child in a straighter position so he can use his arms better and breathe better (see p. 184).

- **Arm weakness** in time may become a problem for self-care and eating.

You can make a simple aid to help get the hand to the mouth. More ideas of aids for eating and reaching are on p. 402 and 403.



CAUTION: If elbow contractures develop, it is probably better to leave them, as a bent elbow is more useful than a stiff, straight one. (see p. 142.)

It is important to help the child gain interests and skills that he can continue to develop even as he becomes very weak. He should stay in school, if possible, even when he has to go in a wheelchair.

Learning to draw and paint can be fulfilling. In Los Pargos, an organization of families of disabled children in Mexico, 4 brothers with muscular dystrophy have all become very good artists. Their paintings have won prizes in contests and are sold to raise money for the group. The best artist of all was the oldest brother, Tito. He took pride in his paintings and enjoyed teaching the other children. He did one of his best paintings, a sea turtle with wings, a week before he died, at age 17.



Even when he was so weak he could barely move, Tito continued to create beautiful pictures.

PREVENTION: The only way to prevent muscular dystrophy is for women who may have the dystrophy gene not to have children. This mostly means sisters of affected boys and close relatives on the mother's side. If you have one son with dystrophy, other sons will be likely to have it too. You might consider not having more children.

OTHER MUSCULAR DYSTROPHIES AND MUSCULAR ATROPHIES

The type of dystrophy just described – also called progressive, pseudohypertrophic, or Duchenne's muscular dystrophy – is the most common. But here are many different types of muscular dystrophy and muscular atrophy. All start little by little: some in early childhood, some between ages 13 to 19, and some in adults. All steadily get worse and worse. Some types, however, almost stop after a certain age, and the person may live to active old age, although handicapped.

CHAPTER 11

Club Feet, Flat Feet, Bow Legs, and Knock-Knees

WHAT IS A DEFORMITY AND WHAT IS NORMAL?

Sometimes parents worry because they think a part of their child's body is abnormal or deformed. But **in small children,often what seems unusual is within what is normal,** and will get better as the child grows. For this reason, it is important to know what variations are normal and which may be problem.

Note: For children born with parts of their bodies missing or shortened see Chapter 12 on birth defects.

1. Many children are born with their **feet somewhat bent or crooked.** To learn the difference between a normal bend caused by the baby's position in the womb, and true club feet, see the next page.



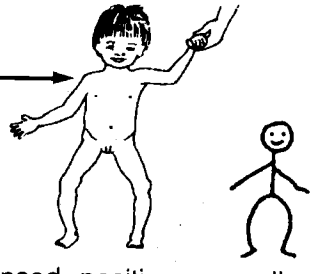
CURVED FEET: NORMAL in the first weeks or months of life.

'FLAT' FEET NORMAL until age 2



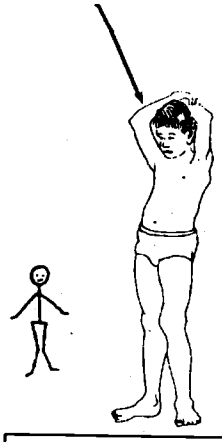
2. 'Fat' or 'flat'?— When most babies begin to walk, they walk on the insides of their feet, with their legs wide apart. Also their feet still have baby fat on the bottom. As a result, the feet look very flat. In nearly all cases, they will get better by themselves. (See p.131).

3. A baby's legs often bend outward (bow legs), like this → This bending starts to disappear at the age of 18 months. Then the legs slowly straighten until they actually bend inward a little, like this.



BOW LEGS: NORMAL until about 18 months

KNOCK KNEES: NORMAL between 2 and 12 years



4. This ,knock-kneed, position generally develops around age 2. By age 5 or 6 the knees begin go straighten.

Note: Children with brain damage sometimes develop a ,knock-knee, way of standing or walking. If the child with knock-knees also moves or walks in a stiff or jerky way, or shows other problems, check for signs of brain damage. (See p.37 and Chapter 9 on cerebral palsy).

IMPORTANT: **In any child who develops bow legs or knock-knees, check for signs of rickets and other problems. See Chapter 13.**

CLUB FEET

About 3 out of 1,000 children are born with a club foot (or feet). Sometimes it runs in the family, but usually the cause is unknown. It is commonly believed in villages that it is related to the eclipse, diet or that it is the fault of parents. But this is not correct.

Sometimes, a newborn baby's feet turn inward, just because they were in that position in the mother's womb.

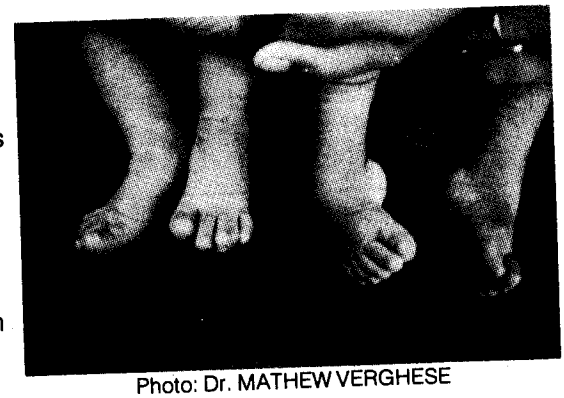
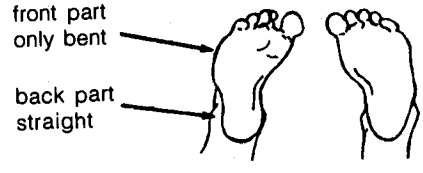


Photo: Dr. MATHEW VERGHESE

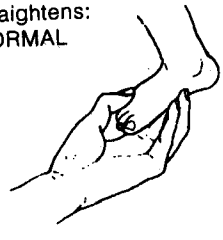
If the front part of a baby's foot is turned inward, it will often straighten out by itself before she is 2 years old.





To find out whether the condition is likely to correct itself,or if it is a true deformity (club foot) that needs special attention, try to put the foot in a normal position.

Bent foot straightens: NORMAL



If you can easily straighten the foot, and bend it into a position opposite to the way it was turned, the foot probably does not have a bone deformity and will get better by itself. Also, if you scratch the foot lightly, the child often will move it into a normal position.

Bent foot does not straighten: CLUB FOOT



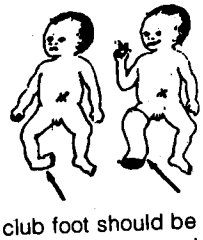
If you cannot put the foot in a normal position, it will need to be straightened with strapping or casts (see Chapter 61.)

Are club feet a sign of some other problem? Although club foot often occurs without any other problem, occasionally it is a complication of spina bifida (problem in the *spinal cord*, see Chapter 22). Always check the child's spine and test if he has feeling in his feet (see p.41)

The feet may also gradually become deformed into a club foot, position, because of cerebral palsy, polio, arthritis, or spinal cord damage.

Rarely, club feet occur together with a 'clubbed hand' or other weakness and deformities of the body. See Arthrogryposis, p.142.

Correcting club feet (For details, see chapter 61.)



A club foot should be held in a cast, or strapped in a straighter position, soon after birth–until it is corrected past normal.



After correcting the foot, daily stretching exercises are often needed to help keep the foot straight.



A brace is used (day and night if necessary) to keep the foot from bending in again.



until finally, **normal use and exercise** keeps the foot straight.



club foot after correction with casts, by village workers (PROJIMO)

About 60% of club feet can be effectively straightened without surgery in 6 to 8 weeks, using either **strapping** or **casts. These methods are described in Chapter 61.**

A child may be brought for treatment at different ages. The chance of getting a normal foot decreases as the child grows older. Treatment started at birth is best.

Sometimes parents are wrongly told that treatment can be started only after the child is 2 years old. So they wait for the child to grow and thus lose valuable time.

Correction of club feet should begin soon after the child is born – if possible, in the first 2 days. At birth, a baby's bones and joints are still soft. As the child gets older, his bones get harder and become less flexible.

Usually, good correction without surgery is only possible in the first year of life. If the deformity is not severe,however, a club foot can sometimes be corrected with casts, even if the child is already 2,3 or even 5 years old or more. But in an older child, it takes longer, surgery is more often needed for good, lasting results.

Some children with very deformed feet will need surgery, even if strapping or casting is done early . However, we have found that some children for whom surgeons have recommended surgery can have their feet straightened with **casts** at a village center.

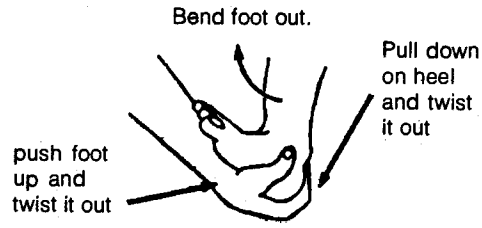
Often the child may have taken treatment but the deformity may have been incompletely corrected or the parents themselves may have neglected the deformity till the child reached school going age, the chances of complete correction become less. Less often, the parents come for treatment when girls have reached marriagable age or for boys they may come when they are ready to seek employment. But by then, often the bones are deformed and surgery may have to be done on the bones to straighten the foot. The foot no longer remains supple, though it may look straight. Some of the older children are best left alone and fitted with a special shoe.

Keeping the feet straight once they are corrected

Once a club foot has been straightened, great care must be taken to keep it straight. The whole family must make sure that the following precautions are taken:

- An ankle brace should be worn **night** and **day** at least until the child is walking, and often until the child **is** 15 or 18 years old.

- Foot-stretching exercises will be needed, especially if there is any sign that the foot is clubbing again. Gently and steadily stretch the foot **past** its normal position in the opposite direction of the deformity. Do this exercise 2 or more times a day.



- Check the foot regularly. Return quickly to the ***rehabilitation*** center for an ***evaluation*** if there is any sign that the clubbing is coming back.

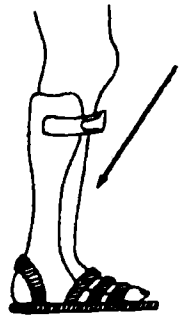
How long will it take?

How difficult it is to straighten a club foot, how long it takes, and how long braces and special exercises will be needed depends on a number of factors:

- **The severity of clubbing.** A severely deformed foot with abnormal bones is much harder to correct.
- **Abnormal muscle balance,** if present, will keep pulling the foot to the inside, even after it is corrected. (See muscle testing, p. 32)
- Generally, correction is more difficult if both feet are clubbed.
- Club feet in **girls** (although less common) are likely to be more difficult to correct than in boys.
- If there are any **other abnormalities** (such as clubbed hand or stiffness in the knees and elbows), club feet may be especially difficult to correct. Usually surgery is needed.
- **The older the child,** the harder it is to correct club foot. Past the age of 2 years, it is often not possible without surgery.
- **Children without feeling in their feet** (spinal bifida) require special precautions and slower correction to avoid pressure sores (see p. 201). Casts, if used, must not apply much pressure, and must be changed often.

If a child's foot shows little or no improvement after 4 weeks of casting, or if improvement stops in spite of continued casting, surgery is probably needed for more complete correction.

BRACES FOR USE AFTER CORRECTING CLUB FEET

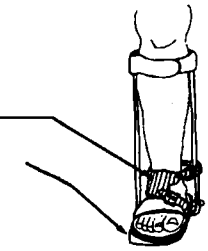


For some feet, a plastic ankle brace may work well

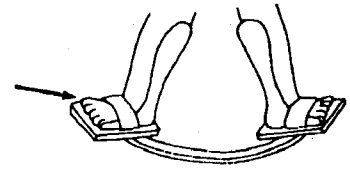
For more difficult feet, a metal brace may be needed, with an ankle strap that pulls the ankle inward.

A slight build-up on the outer edge of the sandal or shoe may also help.

For instructions on making braces, see Chapter 59.



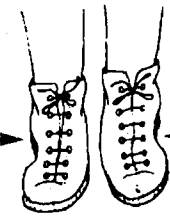
For babies under one year, or small children at night, feet can be held in a good position using a bar that joins the 2 feet. For a simple design, see p.659.



For the child whose feet bend mostly at the middle or front



wearing shoes in reverse may help keep the feet corrected.



left shoe on right foot

right shoe on left foot

INSOLES AND OTHER FOOT SUPPORTS

An insole is a firm pad that is put inside a shoe or sandal to support the arch.



Insoles can be made of leather, porous rubber, or a piece of a car tire, shaping it with care so that it will support the foot comfortably.

Some children with flat feet resulting from polio, cerebral palsy, or Down syndrome may be helped by insoles or other foot supports. But other children will not be helped. Each child's needs should be carefully considered. If after trying an insole for 2 weeks, the child walks with more difficulty, change the insole or stop using it.

Before making the final insole, put a piece of cardboard, wood or some other material shaped like the insole, under the child's foot. Try different heights to find what seems to work best. **Make sure the heel is in a straight line with the leg.**

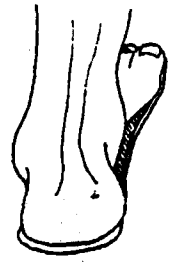
After ,making the insole, check the position of the foot. Do this with the child standing on just the insole, and then with the insole inside the shoe. Watch him walk, and ask him how it feels,. If everything seems right, check it again in 2 weeks.



CORRECT – The heel is in a straight line with the leg.



TOO LOW – The heel tilts outward. The insole should be thicker.

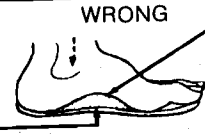


TOO HIGH – The heel tilts inward. The insole is probably too thick.

CAUTION: A person who has a weak ankle and low arch sometimes can not use an insole, because it lets his ankle turn outward as he walks. He may have learned to walk in a way that keeps his ankle from turning out. For such a person, an insole may make walking more difficult, or may force him to brace to keep his foot straight.

IMPORTANT: The thickest part of an insole should be directly under the ankle bone, just in front of the heel, like this.

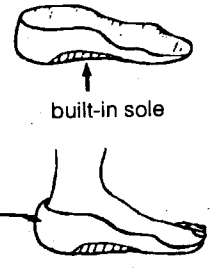




It should not be in the middle of the arch, like this. This can deform the foot more without correcting the problem.

WARNING: Many commercial insoles, and even orthopedic shoes, have the arches in this incorrect position. Check them carefully. If they are like this, do not use them. Also be sure shoes are not so wide that the heel slips to the side.

If the child's foot is flat or very floppy due to paralysis, often an insole is not enough. He may need a short plastic brace that supports the foot like this,



or a brace that supports the foot and ankle, like this.



For instructions on making plastic braces, see Chapter 59.

There is probably only one shoe or sandal alteration that does any good. A small metal plate on the inner edge of the heel stops uneven wear–and may help prevent foot pain.

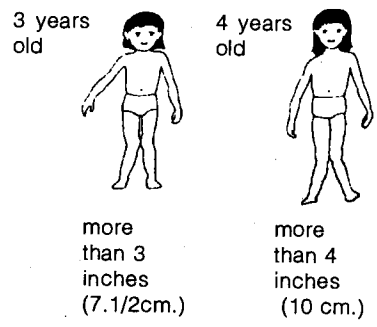


SEVERE KNOCK-KNEES

To check for severe knock-knees, have the child stand with her knees touching. If the distance between the ankle bones is more than **3 inches** in a 3 year old, or **4 inches** in a 4 year old, the problem is probably severe enough to need attention.

If the knock-knees are severe, braces may help straighten the knees and keep the condition from getting worse (see p.659). In a child over 6 or 7 years old, braces usually do not help. In extreme cases, surgery may be needed. Knock-knees may also lead to flat feet.

Sign of a problem



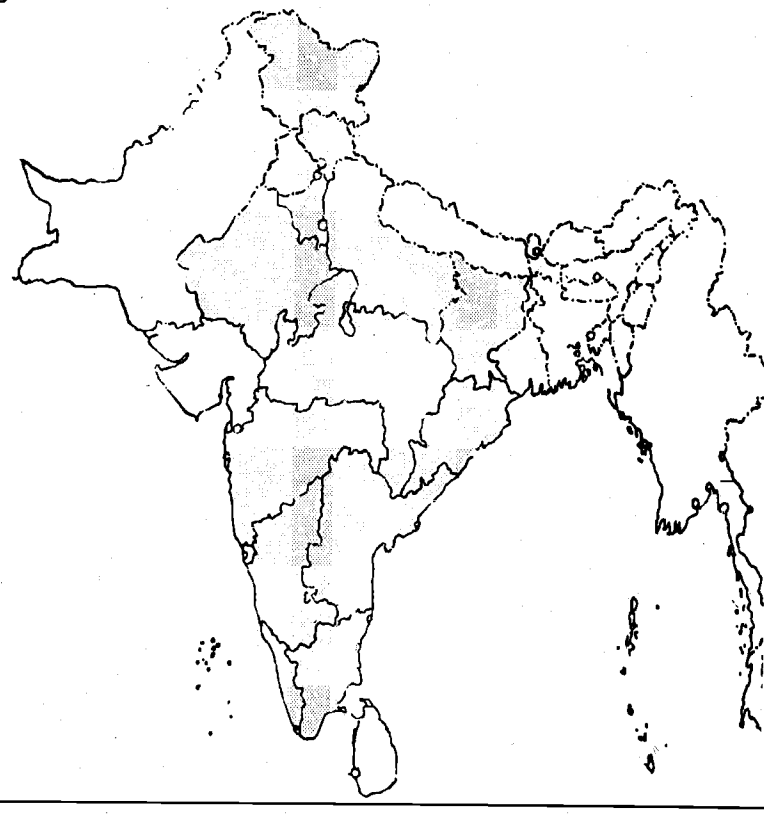
FLUOROSIS

The problem of fluorosis in India has existed for over 50 years. It is estimated that about 25 million people suffer from fluoride poisoning because of environmental pollution. The problem of fluoride poisoning and related health problems is spread over both rural and urban areas in 15 out of the 30 States and Union Territories in the country.

The maximum levels of fluoride which the human body may tolerate is 1.5 parts per million (ppm). This is often based on water fluoride content. In our country 1.00 ppm of fluoride is considered as the upper limit but lower the better. This is because food items besides cosmetics are heavily contaminated with fluoride.

Map of endemic state

Andhra Pradesh
Bihar
Delhi
Gujarat
Haryana
Karnataka
Maharashtra
Madhya Pradesh
Orissa
Punjab
Rajasthan
TamilNadu
Uttar Pradesh
Jammu and Kashmir
Kerala



Severe Knock knees can also be caused by flouride poisoning. A person can be affected by fluorosis in many different ways. Fluorosis is caused by consuming high quantities of fluoride through water, certain foods, cosmetics (toothpaste), drugs as well as inhaling air poisoned by fluoride in industrial environment.

Although there are several sources of fluoride intake, it is believed that the highest intake of fluoride is through drinking water.

Besides water, food items, specially agricultural crops grown in endemic areas are heavily contaminated with fluoride because the earth's crust has fluoride containing minerals in huge quantities. **There is a high content of fluoride in rock salt, pan, supari (beetle nut), tobacco and tea.**

Though the Indian way of preparing tea with calcium rich milk reduces the harmful effects of fluoride, care should be taken to avoid boiling water with tea leaves for a long time and drinking concentrated tea. It is also important to test the crops grown in each district so that it is possible to avoid eating high fluoride containing crops or eat them less often.

Fluoride, when consumed or inhaled in excess can cause a variety of health problems affecting the young and the old alike. Some of these problems lead to disability.

Fluoride poisoning can make a person suffer from any of the following conditions-

- **Skeletal Fluorosis (affecting the bones) or,**
- **Dental Fluorosis (affecting the teeth) or,**
- **Non-skeletal forms (other health problems) or,**
- **a person may have all these or a combination of some of them.**

Skeletal Fluorosis

This is the most disabling of all conditions. A person suffering from skeletal fluorosis needs a lot of help in moving around because his bones and joints have been damaged by the disease. He cannot do many of the things that a normal healthy person can do.

Skeletal fluorosis affects young children as well as older people. Fluoride is particularly harmful to the pregnant and nursing mother because it can harm the unborn baby. Many babies are born with deformities in the endemic areas. Abortions and still births are also common.

Signs that show that a person has skeletal fluorosis

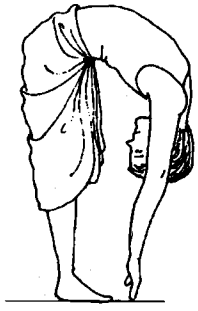
- Severe pain and stiffness in the neck
- Severe pain and stiffness in the backbone.
- Severe pain and stiffness in the hip region (pelvic girdle)
- Severe pain and stiffness in the joints

How to test for these signs

People affected by fluorosis are unable to do many of the functions that unaffected persons can do and are also unable to answer correctly when asked about pain and stiffness in the different parts of the body. This is, particularly true of those living in the rural areas.

A simple test has been devised for detection of complaints regarding fluorosis (Dr. V. K. Desai, Associate Professor, Department of Preventive and Social Medicine,Government Medical College, Surat,Gujarat.)

Normal person can do



He can bend his body and can touch his toes or floor.

person with skeletal fluorosis cannot do

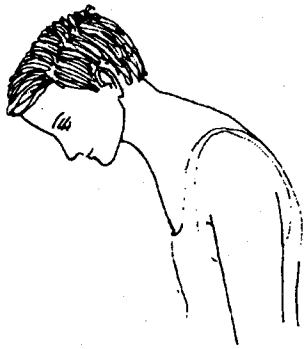


He cannot bend without folding his knees

If there is pain or stiffness in the *backbone* and hip this exercise is not possible



He can touch his chest with his chin.



He cannot bend his neck so he is unable to touch his chest with chin.

If there is pain and stiffness in the *neck*, this exercise is not possible.



He can stretch the hands, fold arms and touch back of head.



He cannot stretch hands, fold arms and and touch the back of head.

If there is pain or stiffness in the *shoulder joint* it will not be possible to stretch the arms sideways, fold them and try to touch the back of the head.

CAUTION: Pain in the neck, back and joints can also be due to other orthopaedic conditions such as Spondylosis, Ankylosis, Spondylites, Arthritis etc. Therefore it should not be concluded that the complaints mentioned above are always due to Fluorosis. However if a person is living in an endemic area for a long time and drinking fluoride containing water, fluorosis should be suspected. If the source of fluoride ingestion is identified namely in water, food, drug or in any thing else, and if withdrawn, the complaints of neck, back or joint pain may still be there; but is unlikely to worsen.

Dental fluorosis is quite common in children who are born and brought up in communities where there is high intake of fluoride. Dental fluorosis can occur in milk as well as in permanent teeth.

Signs of dental fluorosis

- Teeth develop yellow-white spots and become dull.
- Gradually it turns brown and shows up in horizontal streaks. If the discolouring is in the tip of the teeth, it would mean the child has been exposed to high fluoride in food or water or both upto the age of 2. If the discoloration is in the middle of the teeth, it denotes that the child has been exposed to fluoride during the age of 2-4 years. The discoloration near the gums is due to dirty teeth. The brown streaks in the upper part of the teeth show that the child has been exposed to high fluoride from 4 -6 years of age.
- In the later stages all the teeth may become black. They may get pitted and may even chip off.
- There is loss of teeth at an early age.

Other health problems

Gastro-intestinal problems are considered to be the early warning signs of fluoride poisoning. There is severe stomach pain, constipation,diarrhoea, blood in the stool, bloated feeling (gas) tenderness in the stomach and feeling of nausea (flu like symptoms), mouth sores and loss of appetite. On withdrawl of the source of fluoride intake, in 2-3 weeks, these complaints dissapear.

Neurological: Functions that are controlled by the brain such as headache, nervousnes, depression, tingling sensation in the toes and fingers, excessive thirst and the tendency to urinate often are present. The urine may be much less in volume, yellow-red in colour and there is also itching in the area.

Muscular problems such as muscle weakness, stiffness, pain in the muscle and loss of muscle power are quite common as fluoride is known to destroy the muscle structure and function.

Allergies such as painful skin rashes, pinkish red or bluish red in colour, round or oval shaped spots on the skin are common in women and children. These spots however fade and clear up in 7-10 days.

> *CAUTION:* However it must be remembered that fluoride is only one of the reasons for these complaints.

PREVENTION

- Flourosis although untreatable can be prevented.
- Pregnant and nursing mothers should use defluoridated water to have a healthy baby.
- Foods rich in Vitamin C should be taken.
- Diet should have enough calcium. Eat foods rich in calcium (such as milk and milk products).
- Avoid all possible sources of high fluoride containing items such as water (water can be defluoridated) food, drugs and toothpaste.
- Pain in the back, hip, or joints should not be overlooked as casual.

When you notice any of these symptoms go to the nearest hospital for help.

How to remove fluoride from water

The technology for removing fluoride from water has been developed by the National Environmental Engineering Research Institute (Nagpur). In this process, known as the Nalgonda Technique, rapid mixing of water with lime, alum and bleaching powder results in clouding of the water. Gradually it settles down with the deposits at the bottom of the vessel. The fluoride content that remains in the water is very little. The water can then be filtered and used for drinking and cooking.

Other ways for getting safe water

Tube wells dug deep into the ground may provide water which may have less fluoride if the earth's crust in such regions has less of fluoride containing minerals.

Water from areas where there is no fluoride can be suitabily purified and supplied for drinking to the affected areas.

Skeletal Fluorosis resulting in the crippling bone deformity in the form of **Knock Knees** (Genu Valgum) has been linked to the construction of dams near areas with high fluoride content in the water. It may be possible to control the problem of fluorosis in our country through the use of irrigation canals.

Water from areas where there is no fluoride can be suitably purified and supplied for drinking purposes to the affected areas. Where canals have been lined with cement as in Coimbatore (Tamil Nadu) the possibility of picking up fluoride by the flowing water may be less.

Studies have shown that a majority of fluorosis affected villages in Andhra Pradesh and Tamil Nadu are situated within a radius of 70 miles and 20 - 25 miles respectively from the Nagarjuna Sagar and Parambikulam Aliyar Dams. The closer people lived to the dams, the more the number of people affected by fluorosis. The number decreased in villages far away from the dam. It was noticed that these fluorosis affected villages were irrigated by the canals of the dams. **Flowing surface water is considered to contain less fluoride compared to ground water.** A study was carried out to test if irrigation canal waters could be utilised to control the problem of fluorosis. It was found that flowing waters of the Nagarjuna Sagar did not pick up large amounts of fluoride even after flowing for over 70 miles through high fluoride containing soils. It was also observed that in all villages tested, the fluoride content of water from the irrigation canals was much lower than water from the drinking water wells. People whose staple diet is rice were less affected by Genu- Valgum as compared to those who ate jowar or bajra.

Sources of information:

1. PREVENTION AND CONTROL OF FLUOROSIS Sub- Mission on Control of Fluorosis, Technology Mission on Drinking Water, Government of India.
2. National Institute of Nutrition, Hyderabad.
3. Proceedings of the Symposium on Fluorosis (Hyderabad, 1974). Paper 54. SOME NEW ASPECTS OF FLUOROSIS IN SOUTH INDIA

For more information contact: Dr. A.K. Susheela, National Coordinator for Health Sector Activities, Sub-Mission "Fluorosis Control Cell", National Drinking Water Mission, Fluorosis Control Cell, Department of Anatomy, All India Institute of Medical Sciences, New Delhi,110029.

NOTES

CHAPTER 12

Common Birth Defects

TYPES OF BIRTH DEFECTS

One out of every 100 or so babies is born with some kind of obvious defect or deformity. There are many different types. In this chapter we describe a few of the most common: **cleft lip** and **cleft palate, extra or joined fingers or toes,** and **short, missing, or deformed limbs.** We also discuss children born with multiple *contractures* **(arthrogryposis).** Please also refer to the chapters on **club feet** (Chapter 11), and **spina bifida** (Chapter 22).

CAUSES

In many cases, the cause of a birth defect is not known. But sometimes a defect may be caused by one of the following:



This girl's mother did not get enough to eat while she was pregnant.

- **Poor nutrition during early pregnancy.** This is thought to be one cause of cleft lip and palate.

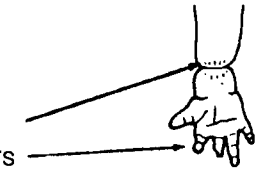
- **Genetic (hereditary).** Sometimes certain defects run in families. For example, if one parent was born with an extra thumb, there is a greater chance that a child will be born with a similar defect. One or both parents may be 'carriers' of the factor that causes a defect, without having it themselves. However, it may be present in relatives. Often both parents must have a 'defect factor' for a child to be born with the defect. For this reason, **birth defects are more common in children whose parents are closely related,** and who therefore carry the same defect factors.



A doctor gave this boy's mother a medicine for 'morning sickness'.

- **Medicines, pesticides, chemicals, and poisons.** Especially during the first 3 months of development, a baby in the womb can easily be harmed by chemicals and poisons. **Many medicines, drugs, and pesticides** (plant, insect, and rat poisons) can cause birth defects if a pregnant mother is exposed to them.

- **German measles.** If the mother gets German measles during the first 3 months of pregnancy, it can cause defects in the baby. These usually affect the senses (hearing and seeing), The brain (cerebral palsy and ***retardation***), or organs inside the body (heart, liver). Sometimes the baby is born with 'rubber band like' grooves on the limbs and deformed or missing fingers or limbs.



- Children born to **mothers 40 years of age or older** are more likely to have Down syndrome and defects of the hands, feet, or organs inside the body (heart, liver).In this age group, about 1 mother in 50 will have a child born with Down syndrome or defects.



This boy's mother was 45 years old when he was born.

For ways to prevent birth defects, see p. 144.

CLEFT LIP AND CLEFT PALATE

A cleft lip (or 'hare lip') is an opening or gap in the upper lip, often connecting to the nostril.

A 'cleft palate' is an opening in the roof of the mouth connecting with the canal of the nose.

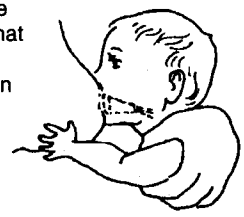


simple cleft lip | double cleft lip | cleft palate

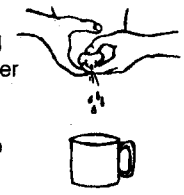
Usually 1 in about 800 children is born with a cleft lip, cleft palate, or both.

Babies with these conditions often have trouble sucking, and may choke or gag on food that gets into their nose. Usually breast feeding is the best way to feed these.

Put the breast deep into the mouths so that the milk comes out on the back of the baby's tongue.



Occasionally the mother may need to get milk from her breasts by squeezing them, and then feed the milk to her baby with a spoon.



To prevent choking, feed the baby while he is sitting up with his head tilted forward a little.



Make every effort to have the defects corrected by surgery since this can greatly improve the child's looks, eating ability, and speech. **The best age for surgery** is usually at **4 to 6 months for the lip** and about **18 months for the palate.**

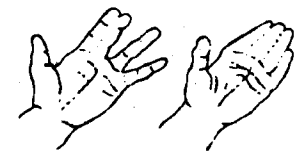
To prepare for surgery, parents should frequently stretch **the deformed lip,** so that the 2 sides meet in the middle.



Even after the cleft lip and palate have been successfully repaired, speech problems often occur. The family should gently encourage the child to speak as clearly as she can. Lip and tongue exercises may help (see p. 384). The child who cannot get surgery may need to learn sign language, using her hands to help people understand her (see p. 320).

JOINED FINGERS AND EXTRA OR DEFORMED FINGERS OR TOES

Some children are born with 2 or more fingers joined together. This does not cause much difficulty in use of the hand. However, special surgery can often separate the joined fingers.



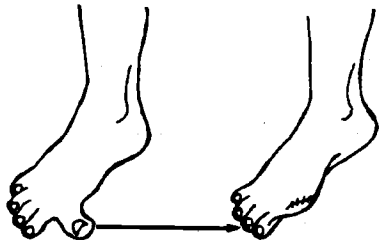
When a child is born with a small extra finger or toe that has no bone in it, you can tie a string tightly around it, like this. In a few days the finger will dry out and fall off.



Larger extra fingers or toes, if they get in the way can be removed by a surgeon.



A child who is born with a toe that sticks out may need surgery in order to wear shoes. The toe can sometimes be put straight. At other times it may be simpler to remove it.



To get the best results, the surgery should be done by a specially trained ***orthopedic*** or plastic surgeon.

INCOMPLETE OR MISSING ARMS OR LEGS



Sometimes medicines a mother takes early in pregnancy cause a child to be born with missing or incomplete arms or legs, or both.

A child born without arms but with normal legs and feet can often learn to use his feet almost as if they were hands: for eating, writing, drawing, playing games, and doing many kinds of work.

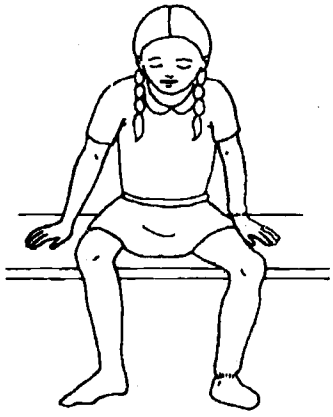
It is important to encourage the child to use her feet, or whatever part of her body possible, to do everything she can for herself.



The child who is born with incomplete arms and legs can be helped a lot by **artificial arms with hooks for grasping** (see p. 273).

We do not give instructions for making these arms in this book, as they are fairly complicated. However, try every possibility to get artificial arms for the child. They can make a very big difference in her life. If possible, the child should get her first limbs by age 3.

For ideas about aids and artificial limbs for children born with missing or defective hands and feet, see Chapter 27, "Amputations." and Chapter 68, "Artificial Legs."

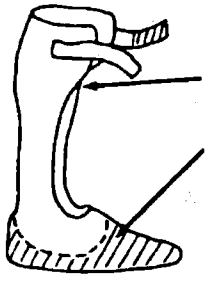


This little girl was born with 'rubber band-like' constrictions in her hand and leg, and with parts of her fingers and foot missing. The deformities happened because her mother had German measles when pregnant.



Her foot looked like this.

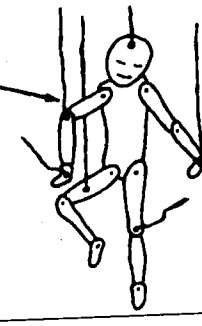
Village *rehabilitation* workers made her a plastic brace with a partial foot built into it, so she could wear a regular shoe or sandal.



A firm foam-plastic foot was shaped and attached to a plaster mold of the foot (see Chapter 59). The plastic brace was heat molded over this.

ARTHROGRYPOSIS (Multiple contractures from birth)

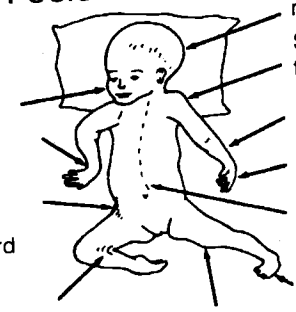
Arthrogryposis means 'curved joints'. Children with this ***disability*** are born with stiff joints and weak ***muscles***. The strange position of arms and/or legs may give a child the look of a wooden puppet.



In some children, both arms and legs may be severely affected. In others, only the legs or feet, or hands or arms may be affected.

A child born with clubbed feet and with one or both arms stiff with hands turned out, may have arthrogryposis.

TYPICAL BABY WITH ARTHROGRYPOSIS



The **cause** of arthrogryposis is not known. It may be a *virus* infection of the mother, the mother, during pregnancy. Arthrogryposis is a **rare condition** in most of the world, but for unknown reasons, in parts of Central and South America it occurs more frequently. (In PROJIMO, in Mexico, 1 of every 100 disabled children seen has arthrogryposis.)

Rehabilitation of the child with arthrogryposis aims at helping the child do as much for herself as possible.

Some children with arthrogryposis are able to walk, especially if contractures are corrected. Correction of club feet (see p. 128) and hip and knee contractures should begin gradually, and without forcing, soon after birth, with casting (see p. 689), positioning, and/ or range-of-motion exercise (see p. 128).



TYPICAL STANDING POSITION OF A CHILD WITH ARTHROGRYPOSIS

If both hips are dislocated, surgery to put the bones back into their sockets is not usually helpful. The child walks as well without surgery. If only one hip is dislocated, surgery may help.

Often, however, contractures of arthrogryposis can only be corrected by surgery. The possible benefits – and losses – which surgery may bring should be carefully evaluated. For example, a stiff elbow in a bent (contracted) position may be much better for eating than an elbow that has been straightened, and will not bend.

MORE USEFUL LESS USEFUL

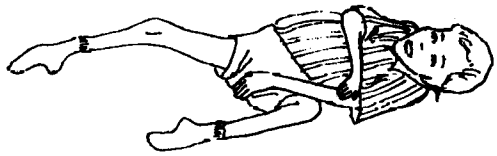


WARNING: A STIFF ELBOW IS OFTEN MORE USEFUL LEFT BENT

Most children with arthrogryposis are very intelligent. If given a chance, many can learn to do a lot of things for themselves, even with *severe disability*. Often they try hard and are eager to learn. **It is very important that these children be encouraged and helped to do as much as they can for themselves, and that they go to school.** The following story may help give you an idea of the possibilities of a child with arthrogryposis.

SIMPLE STEPS TOWARD INDEPENDENCE – A true story

Gabriel is 7 years old. He lives with his family in Mazatlán, Mexico. he was born with arthrogryposis. Some of his joints are stiff and straight, others are stiff and bent. He lacks most of the muscles in his arms, legs, and hands. He cannot sit alone or lift a hand to his mouth.



Gabriel's parents love him dearly and care for him tenderly. However, when he was born, doctors told them that nothing could be done for him. So his parents grew used to doing everything for him. As he grew older, they carried him in their arms, changed his *diapers* when he dirtied them, and gave him food in his mouth. They treated him like a baby – though he no longer was one.

When his mother learned of PROJIMO, she took Gabriel there, hoping that with surgery or special medicine, he might improve. The village *rehabilitation* workers at PROJIMO investigated all possibilities. They even took him to a famous hospital for disabled children. But the specialists said they could do nothing for Gabriel.

Fortunately, therapists who were visiting PROJIMO as instructors explained to the team that in fact there was a lot that could be done, not to help Gabriel walk, but to help him do more for himself – within his possibilities. The team began to work with the family, to help Gabriel become more independent.

Now, with the help of the village rehabilitation workers and his family, Gabriel is able to meet some of his basic needs for himself. He feels less like a baby and more like a young man. he has stopped using diapers; he asks when he needs to go to the toilet. He has learned to use his mouth like a hand, to hold and do things.

He has learned to feed himself. He swings his arm onto the table using his neck muscles, and hooks his hand over a spoon. Using the edge of the table and the rim of the dish to push against, he see-saws the spoon to his mouth. To drink he uses a straw with a bend in it.



Gabriel's family has joined Los Pargos, an organized group of families of disabled children. he attends school in a specially-adapted wheelchair that he can move himself. He is learning to read, write, paint pictures, and to play with other children.

There is much more that Gabriel and his family will be able to achieve, now that they all see how much he can do for himself. Gabriel is happy and eager to learn more.



Gabriel wrestling with another disabled child.

Various aids and ***adaptations*** can help children with arthrogryposis or similar disabilities become more independent:

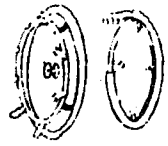
Eating aids are described on p. 402 to 404



Writing aids are shown on p. 5, p. 273, and p. 607.



Wheelchair aids are shown in Chapter 65.



PREVENTION OF BIRTH DEFECTS

It is not possible to prevent all birth defects. There are, however, ways to make it less likely that children will be born with birth defects.

- **Eat well during pregnancy.** (See p. 13 and *Where There Is No Doctor,* Chapter 11.)
- **Avoid marrying close relatives. If you already have one or more children with a birth defect, consider not having more.**
- **Avoid all medicines during pregnancy** unless you are sure they will not damage the baby. (Aspirin, vitamins, some antacids, and iron in the correct dose are all right.) Avoid any contact with pesticides and other poisons. Tobacco and alcohol during pregnancy can also damage the developing child.
- While pregnant, stay far away from children with German measles if you have never had it. If you are not pregnant, try to catch it before you get pregnant. ***Vaccine*** exists for German measles, but is not often available.
- Consider not having more children after age 35 or 40, or if you have had one child with Down syndrome, since the chance of having another is increased.



A child with brittle bone disease. (Photo By Philip Kgosana)

CHAPTER 13

Children Who Stay Small or Have Weak Bones

In this chapter we look at children whose bones are weak and deformed, and at children who do not grow as tall as other children. We include **rickets, brittle bone disease,** and **children who stay very short** (dwarfism). In all of these conditions, **the legs may become bowed,** and the shape or proportions of the bones are often not normal.

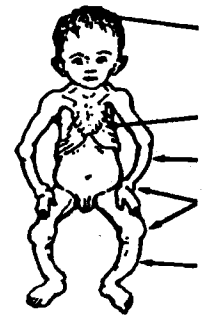
RICKETS

Rickets is weakness and deformity of the bones that occurs from lack of vitamin D. Vitamin D occurs in whole milk, butter, egg yolks, animal fats, and liver, especially fish liver oil. The body also makes its own vitamin D when sunlight shines on the skin. Children who do not eat enough foods with vitamin D, and who do not get enough sunlight, gradually develop signs of rickets. Rickets can occur in children at an early age. It can also affect older children and adults.

Rickets is fairly common in some countries, especially in cool mountain areas of Asia and Latin America where babies are kept inside and wrapped up. Rickets is also increasing in crowded cities where children are seldom taken into the sunlight.

Treatment for rickets is to give fish liver oil, and to spend time in the sunlight. The best and cheapest form of **prevention** is to be sure sunlight reaches the child's skin. Foods that contain vitamin D also help.

SIGNS OF RICKETS



BRITTLE BONE DISEASE

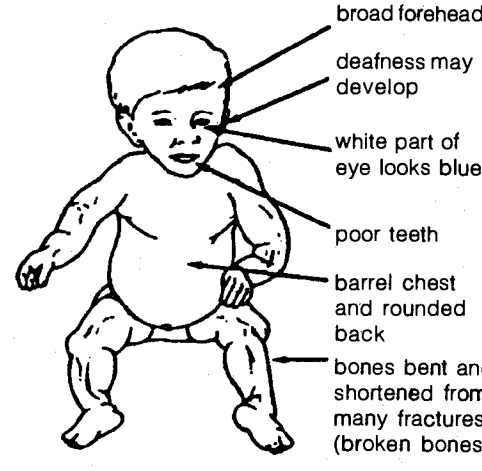
The child is born with bent or twisted limbs, or with broken bones. (Or he may seem normal at birth, and the bones begin to break later.) He may start to walk at near the normal age, but increasing deformities due to breaks may soon make walking impossible. Because of the many broken and bent bones, these children stay very short. Parents sometimes do not realize when their child breaks a bone.

Brittle bone disease is not common. Sometimes it is ***inherited,*** and someone else in the family will have the same problem.

There is no medical treatment. However, sometimes surgery can be done to straighten and strengthen the leg bones by putting a metal rod down the middle of them. This may help the child walk for longer, but he may eventually need a wheelchair to move about. Back problems increase with age; a body brace may help (see p. 184).

Children with brittle bone disease are often intelligent and do well in school. Increasing deafness may become a problem. Help them to develop their minds and learn skills that do not require physical strength. The child must learn how to protect his body from breaks. It helps to sleep on a firm bed.

SIGNS OF BRITTLE BONE DISEASE



CHILDREN WHO STAY SHORT (Dwarfism)

Parents often worry when a child does not grow as quickly as other children. Shortness has many causes. Here we discuss only a few.

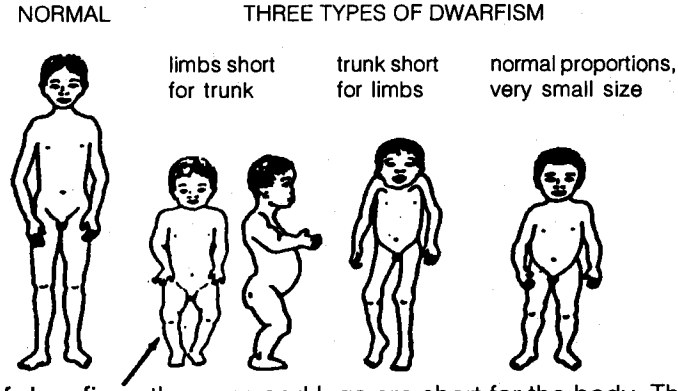
- **Normal slow growth.** Some children normally grow more slowly and mature sexually later than others. If the child is normal and healthy in other ways, do not worry. He will probably grow quickly when he begins to grow up sexually, even if this happens as late as 15, 16, or 17 years old.

- **Normal short size.** When one or both parents are shorter than average, they may have children who are also short. Shortness 'runs in the family' and this is normal. Make sure the child is healthy and eats well.

- **Poor nutrition.** Some children do not grow normally because they do not get enough to eat, or do not eat the food their bodies need. They may seem normal except that they are thin, small, have big bellies, and get sick often. Or they may lack energy, seem very unhappy, or develop swollen feet, hands, and faces. These children need more and better food (see p. 393). They may also need more stimulation, play, love, and attention in order to grow and develop more quickly (see Chapter 36).

- **Long-term illness or medication.** Severe long illness often slows down a child's growth. Also, certain medicines such as cortisone or steroids for arthritis, if given for a long time, can slow down growth and weaken bones.

- **Dwarfism.** Some children are born with a condition in which the body does not grow normally. There are many different patterns and causes. In 1 of 5 children it is inherited, and certain relatives will also be very short.



In the **most common type of dwarfism**, the arms and legs are short for the body. The head is big, the forehead bulges, and the bridge of the nose is flat. The child often has a swayback, pot belly, and bowlegs. Hip problems, club feet, or eye problems and hearing loss may occur.

TREATMENT

There is no medical treatment for most children who are short, including those with dwarfism. In many countries, doctors prescribe 'growth' hormones to short children to make them grow faster. These may cause some growth at first, but they soon make the bones mature and stop growing, so that the child stays smaller than he would have without treatment. **Do not give hormones to speed growth.**

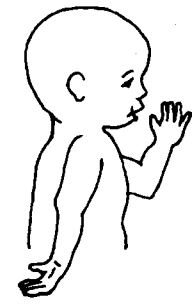
Children who are very short for their age sometimes are made fun of by other children, or get treated as though they are younger than they really are. Life can be difficult for them and they may feel unhappy or unsure of themselves. It is important that everyone treat them just like other children of their age. CHILD-to child activities can help other children become more understanding (see Chapter 48).

CHAPTER 14

Erb's Palsy

Arm Paralysis from Birth Injury

WHAT IS IT?



Erb's palsy is a ***paralysis*** of the muscles in a baby's arm caused by injury of the *nerves* in the shoulder at birth (during delivery).

The baby lies with one arm and hand twisted backward and does not move the arm as much as the other.

If the injury is not severe there may be some recovery. If it is very severe there may not be any recovery.

If the full range of motion of the arm is not kept through regular exercise, *contractures* will develop that may prevent lifting the arm above the shoulder or turning the hand palm up.



Severe Erb's palsy in 14 year old boy. This is as high as he can lift his arm.

Sometimes when small children are lifted by their forearms, one of the bones of the forearm can partially dislocate from the elbow. (This is called a pulled elbow). The child is often brought with an inability to move the limb and she may be wrongly diagnosed as having paralysis, Erb's or Polio. If there is doubt about the condition ask the parents whether the child was lifted by the forearm.

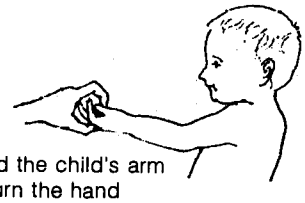
Bending the elbow to the right angle and quickly rotating the forearm clockwise and anti clockwise will set the elbow right.

How common is it?

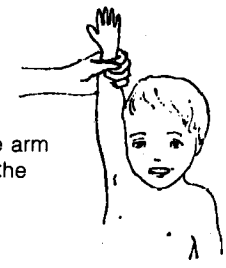
Nerve damage causing Erb's palsy occurs in approximately 1 out of every 400 births. It is much more common in babies who are born bottoms first (breech) because the shoulder is easily stretched and the nerves injured.

What can be done about it?

With the baby, start range-of-motion exercises 2 times a day.

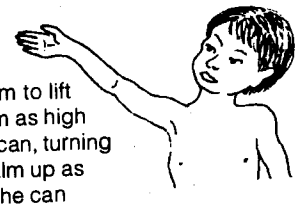


Extend the child's arm and turn the hand upwards



Then raise the arm straight over the child's head.

When the child is old enough, have him do exercises himself, for range of motion and to increase strength.

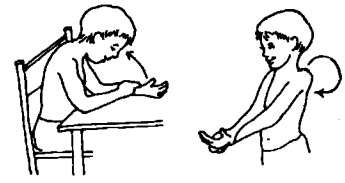


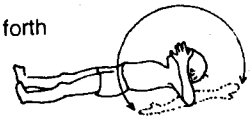


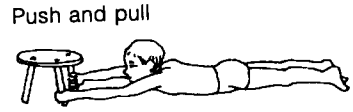
Note: If contractures have already formed, do exercises more often, for a longer time. Each time try to turn the hand up and lift the arm as high as possible. Hold it in the stretched position while you count to 25, or sing a song.

Other helpful exercises

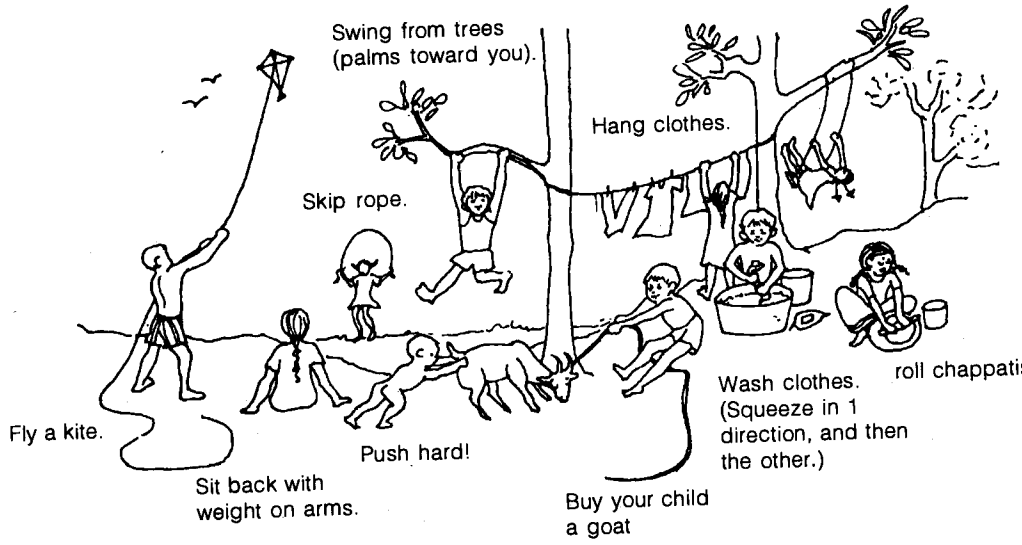








Look for ways to include these exercises in work and play.



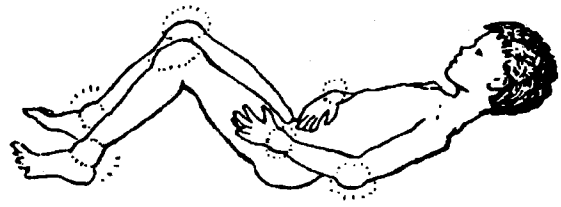
PREVENTION

Erb's palsy can sometimes be prevented if the midwife or doctor takes care not to strain or force the baby's shoulder when being born. Examination of the mother's belly before birth should let the midwife know if the baby is likely to be born breech. In this case a hospital delivery by a skilled doctor or midwife may reduce the chance of injury.

Contractures and significant ***disability*** from Erb's palsy can largely be prevented by exercises. Some weakness may last throughout life.

CHAPTER **15**

Painful Joints



Joint pain in children has many causes. Depending on the cause, different treatments may be needed. The chart that follows will help you decide what the cause of **chronic** (long-lasting) joint pain in a child might be. However, other less common causes may also be possible. Sometimes laboratory tests may be needed to be more certain.

Specific treatment is needed for certain kinds of joint pain – especially those caused by ***infection.*** However, some basic principles of care and ***therapy*** apply to most joint pain, regardless of the cause. Following the chart of causes, you will find some general guidelines for the care of joint pain. These guidelines are described in more detail in Chapter 16 on juvenile arthritis.

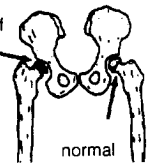
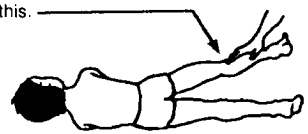
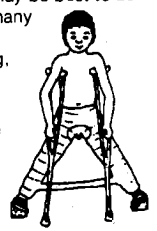
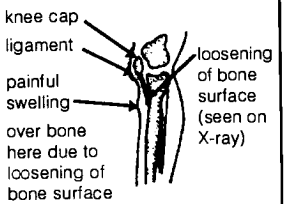
Three chapters on disabilities with joint pain are "Juvenile Arthritis"(Chapter 16), "Rheumatic Fever"(Chapter 17) and "Hip Problems"(Chapter 18). However, arthritis (joint pain and damage) can occur with any ***disability*** where paralysis or ***muscle imbalance*** cause abnormal positions or twisting of joints. Many children with polio develop painful **dislocations** or when, they are older, arthritis.

NOTE: The chart does not include the many ***infectious*** diseases that may cause ***temporary*** joint pain. These do not usually lead to long-term disabilities. For details of diagnosis and treatment of illnesses that cause temporary joint pain, consult a health worker or see a medical text such as ***Where There Is No Doctor.***

> *CAUTION:* **Try not to confuse similar illnesses.** Two of the most common causes of joint pain in children are **rheumatic fever** and **juvenile arthritis.** Even some doctors and health workers get them mixed up and diagnose juvenile arthritis as rheumatic fever. The two illnesses do have similarities. However, rheumatic fever almost always follows a period of sore throat with fever. **If the child did not have a sore throat, probably the joint pain is not due to rheumatic fever.** When in doubt, however, 10 days of penicillin pills may be a wise precaution.

Carefully study the differences between the common causes of joint pain. If you are not sure, seek help from someone with more experience.

COMMON CAUSES OF CHRONIC JOINT PAIN IN CHILDREN (pain that lasts more than 2 weeks or keeps coming back)

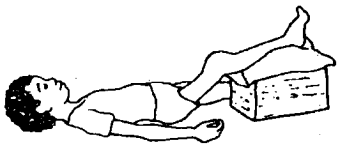
Problem	Age it often begins	Pain in one or in several joints	Fever	Other signs	Treatment and therapy
rheumatic fever (see Chapter 17)	5 to 15 years old	Usually pain is in **several** joints, (Rarely it begins with severe pain and **swelling** in only one joint, but often there is also some pain in other joints) Often pain starts in ankles and wrists, then knees and elbows. Pain may change from some joints to others. 	High fever is typical (usually starts suddenly) 	• Joint pain and fever usually begin 1-3 weeks after severe sore throat with fever (strep throat). • Small lumps may appear under the skin over joints. • sometimes wiggly reddish circles on skin in severe or advanced cases, heart problems ('heart murmur', difficulty breathing, or chest pain) • usually gets better in 6 weeks to 3 months–but likely to come back.	• penicillin for 10 days each time throat gets sore (or continuously if heart is affected) • aspirin in high doses with precautions (See p.154) • rest • range-of-motion (ROM) exercises • Apply heat or cold to painful joints.
juvenile arthritis (also called juvenile rheumatoid arthritis or Still's disease) (See Chapter 16).	Any age, but often begins between 2-7 or 9-12 years old Lasts for years (Often the arthritis gets better when child becomes sexually developed).	May affect **few** joints, **many** joints, or almost **all** joints rarely. (In 1/3 of children it begins in only one joint–later it may affect others). 	Often some fever when pain is worst. (Rarely, it begins with high fever) 	• Usually no history of sore throat • severely painful, hot,swollen, joints often. leading to muscle weakness, contractures and deformities • sometimes a rash that comes and goes • may begin little by little, or suddenly and severely  • morning stiffness • one or both eyes may become red and sore (iritis) and become damaged • usually lasts for years with periods when it gets better and then worse.	• aspirin in high doses with precautions to avoid stomach upset (See p.154) • Apply heat or cold to painful joints • ROM exercises • exercises without motion to strengthen muscles • lots of rest, but also moderate activity • lots of understanding and support.
destruction or slipping of cap of thigh bone at the hip (See Chapter 18)	Destruction: mostly boys 4-8 years old Slip: mostly boys 11-16 years old	pain in one **hip** (rarely both) Destruction: Cap of head of thigh bone breaks into pieces and gradually re-forms in 2 to 3 years  normal X-ray needed to make definite diagnosis	no fever	• child begins to limp–often without complaining of pain • may complain of pain in knee or thigh (or sometimes hip) gradually develops weakness for raising leg like this. 	• For destruction, it may be best to do nothing, although many specialists still recommend casting, braces or surgery. • For slip: surgery to pin the cap into the right place may be needed. 
below-knee pain (Osgood Slater's problem)	Boys 11-18 years old	usually **one** knee only 	no fever	• especially in very active, strong boys • may begin with pain after jumping, running, or forceful exercise.	• Avoid forceful exercises or activities until pain goes away (usually in 2 to 3 years) • aspirin and hot (or cold) soaks for pain • The problem may last for years but in time will go away, although the bony bump remains.

'hot' infection of a joint (bacterial infection: staphylococcus, streptococcus, typhoid, etc)	any age, but rarely in very young children	**one** hip,knee or ankle joint rarely more than one joint	often low fever, sometimes high fever, at least at first	• sometimes follows injury to joint or illness such as typhoid • usually begins suddenly • joint often red, hot, swollen • joint destruction may be severe–leading in time to a fused or 'frozen' joint or dislocation.	• Identify cause of infection (lab tests needed). • Treat with appropriate antibiotic. • Apply splint to avoid motion and activity during early stage. • Refer to a surgeon for drainage of pus.
'cold' or 'slow' infection of a joint tuberculosis (TB), (or less commonly, syphilis, gonorrhea, or fungus–which are not discussed here)	any age, but mostly in older children and young adults	**one** hip or knee, or in backbone (See TB of spine, p.185) Joint may gradually become large or deformed, but not very hot or red warm, soft swelling often much pain (sometimes no pain until the bone or joint damage is severe)	low grade fever or no fever	• often history of TB in family • only half of these children have signs of lung TB • strongly positive TB skin test (test has meaning only in children not vaccinated against TB) • child often quite thin or sickly (but not always) • Pain usually begins little by little and may become so bad that the child cannot move his leg. • Night cries and sweating	• anti-tuberculosis medicines (2 or 3) for at least 1 year (See ***Where There Is No Doctor,*** p.258) • daily ROM exercises • aspirin and hot soaks for pain • exercises-without-motion' to keep muscle strength. • May require an operation to drain pus
sprains and **torn ligaments**	older child or adult	**one** joint only hot and swollen at first	no fever	• Ankles and knees are common sites • often results from forceful twisting • Joint may be loose or floppy, and remain weak for months or years. It may easily be twisted or injured again	• Apply cold during first day after sprain, following days, apply heat • Avoid motion, but keep joint in good position • aspirin for pain • Provide temporary support with elastic or adhesive bandage or (in severe cases) a cast or ankle brace.
injury to joint surface (for example: torn meniscus,bursitis)	older child or adult	usually one joint only, often the knee	no fever	• usually after twist or strain or injury • may hurt suddenly or go weak at certain times but not at others • Swelling or 'liquid' under skin may form behind knee or on the edge of joint	• Provide support with elastic bandage • rest, moderate activity • gentle ROM exercises • aspirin for pain • If problem continues, seek help of a specialist.
dislocated joint due to injury (dislocation is when a bone comes out of its socket)	at birth or in older child	**one** joint Hips, shoulder, and elbows are most common.	no fever	• at first, very painful and weak • In weeks or months (if uncorrected) pain becomes less but weakness often remains • Joint looks deformed	• Have an experienced person try to put the bone back in its socket (the same day or soon after the dislocation occurs). Older dislocations and some new ones may need surgery. • Provide support for a few weeks with elastic bandage (especially shoulders and knees). • Gently do ROM exercises every day.
dislocated joint due to muscle weakness or muscle imbalance	occurs in older child with polio, other paralysis, or arthritis	usually one joint weak shoulder dislocated from weight bearing pain mild to severe, often occurs with weight bearing and increases with time.	no fever	• deformed (strangely shaped) joints • Knees, shoulders, hips, feet, elbows may gradually dislocate because muscles pulling them in one direction are stronger, or because muscles surrounding the joint are so weak. • Careless stretching exercises may cause or increase dislocation.	• Try to put dislocated joint back into place. • Avoid positions that force joint out again. • For partial dislocations of knee, careful stretching exercises may help–but take care to avoid further dislocation. (See p.462).

How to care for painful joints

1. REST THE JOINTS

The more painful the joint, the more it needs rest. Some movement is important, but no forceful exercise or heavy use of the joint.



If joints are swollen, it helps to keep them lifted up.

2. HEAT AND COLD

Applying heat (see side box) or cold to the joint often reduces pain and makes motion easier. For cold, use packs of ice wrapped in a cloth or towel for 10 or 15 minutes. Experiment to see which works better. **Usually cold works better on hot, inflamed joints and heat on sore, stiff joints.**

Hot wax can be used instead of hot water. Some specialists say that it does not do more good than hot water, but persons with arthritis find it very soothing.

Heat beeswax or paraffin until it just melts(but not too hot – test it first on a finger)



Dip the hand or painful joints into the hot wax.



Take it out. The wax will quickly harden.



When it cools, dip it in again.

3. PAINKILLERS

Usually aspirin works best, because it **reduces both pain and inflammation.** For doses and precautions, see p.154.



Note: for severe pain, **splints to prevent motion** help reduce pain and prevent contractures.

4. RANGE OF MOTION (ROM) EXERCISES

It is important to move the joints through their full range of motion at least twice a day (especially if splints are used). If it hurts, apply heat or cold first, and move them very slowly. Do not force (See Chapters 16 and 43).



5. EXERCISES WITHOUT MOTION

These are exercises to strengthen muscles without bending the painful joints. For example, a child with a painful knee can keep her thighs strong by tightening her thigh muscles while her leg is straight. She should hold the muscles tight until they get tired and begin to tremble. This will strengthen them and keep them strong. (See p.160 and p.456)



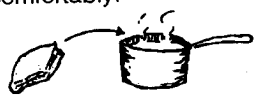
6. CONTINUE DAILY ACTIVITIES

With most joint pain, it is important that the child remain fairly active. She should try to continue with all daily activities that do not strain or overwork the painful joints. Moderate activity is usually recommended (except for acute infections or injuries, when complete rest may be needed for several days).



HOT SOAKS

1. Boil water. Let it cool until you can hold your hand in it comfortably.



2. Wet a thick cloth or towel in hot water and squeeze out the extra.



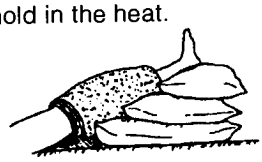
3. Wrap the cloth around the joint.



4. Cover the cloth with a piece of thin plastic.



5. Wrap with a dry towel to hold in the heat.

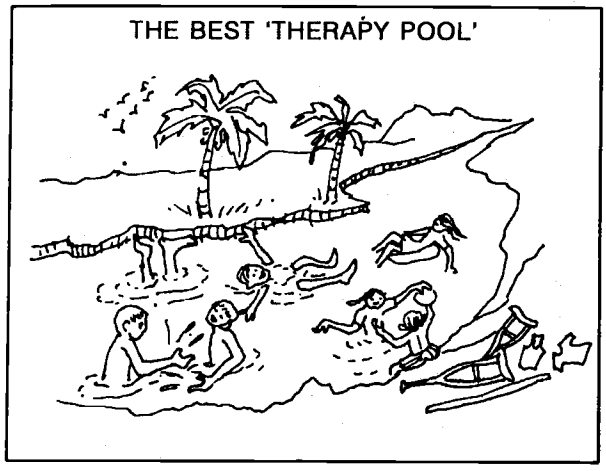


6. Keep the joint raised.

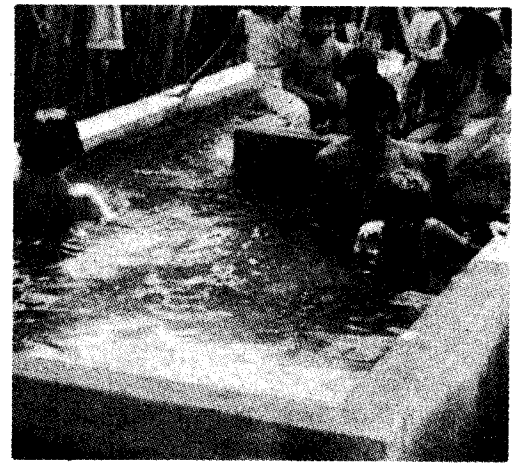
7. When the cloth starts to cool, put it back in the hot water and repeat.

Designs for therapy baths

Floating and playing in water provide exercise and therapy for many kinds of physical disabilities – especially those in which movement is limited because of pain or muscle spasms.



For children who have the opportunity, bathing, swimming, and playing in rivers and ponds with other children is good – but only when the rivers or pools are not dangerous and do not transmit diseases.

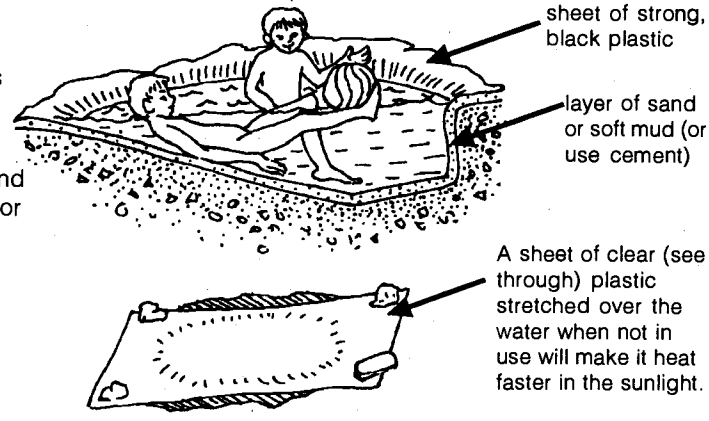


This 'therapy pool' at PROJIMO has one large deep tank for standing, swimming, and play. And it has 2 narrow 'water lanes' at different depths for children to learn to walk while supported by water. Disabled and non-disabled children play here together

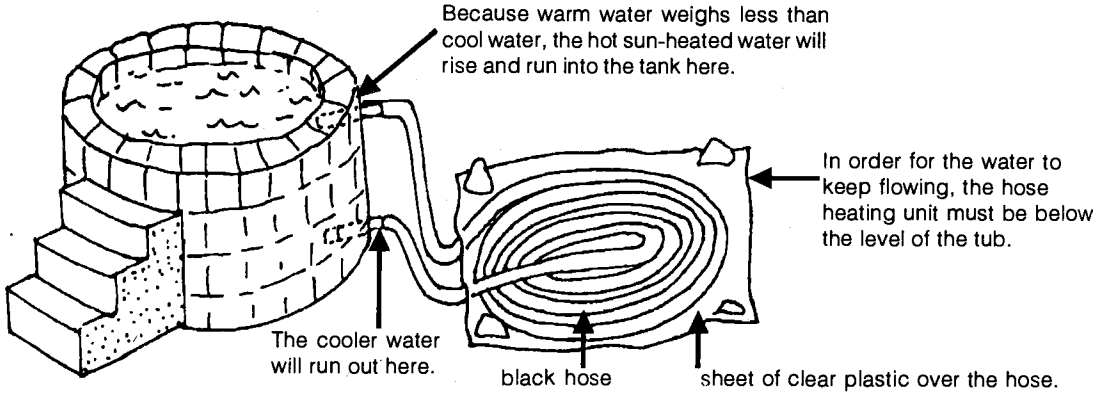
TUBS OR TANKS OF SUN-HEATED WATER (solar heating)

Bathing in warm water is especially helpful. The penetrating heat of the water helps to improve blood flow, calm pain, and relax the muscles.

You can dig a hole in the ground and cover its sides with plastic sheets or cement to prevent the water from leaking out. So that the sunlight heats the water faster, use black plastic, or paint the cement a dark color. (Green is friendlier than black).



TUB WITH A SELF-CIRCULATING SUN HEATER



INFORMATION SHEET ON ASPIRIN FOR PERSONS WITH JOINT PAIN

Aspirin (acetylsalicylic acid) is usually the best medicine for joint pain :

- Aspirin not only helps to **control pain**, it **reduces inflammation**(swelling and damage to joint surfaces). Thus it helps stop destruction of the joints. Many other painkillers do not do this.
- Aspirin is **not expensive**.
- When taken correctly, aspirin has **fewer risks**, dangers, and complications than most other medicines for joint pain.

In order for aspirin to work well without causing problems :

- Take the correct dose at the right times **everyday**.
- Keep taking the same amount of aspirin even after the pain has lessened. This will still help control swelling and let the joints begin to heal.
- Take strict precautions to avoid stomach upset.

PRECAUTIONS

A. Aspirin is an acid. It can cause stomach-ache,chest pain (so-called 'heart-burn'), or even make holes (ulcers) in the stomach. To avoid these problems:

- **Always take aspirin with food or a large glass of water.**
- If this does not prevent stomach pain, take the aspirin not only with food and lots of water, but **also with a spoonful of an antacid such as Gelusil or Magnesium trisilicate**.
- Do not prescribe aspirin to children with **asthma** and those with a history of bleeding (haemophiliacs)

Stop taking aspirin if:

- stomach pain still occurs after following the above precautions,
- you start to vomit blood,
- you start to shit blood, or if your shit looks black tar (digested blood).

B. **Too much aspirin will poison the body**. (The dose that will reduce inflammation is almost as much as the dose that can poison). An early sign of poisoning is ringing in the ears. **If the ears begin to ring, stop taking aspirin until it stops.** Then take it again, but in a slightly lower dose.

C. **Keep aspirin out of the reach of small children**

> *CAUTION;* To prevent choking do not give medicine to a child while she is lying on her back, or if her head is pressed back. Always make sure her head is lifted forward.

DOSES OF ASPIRIN FOR ARTHRITIS AND RHEUMATIC FEVER

300 or 325 mg tablets:
Adults : 2 to 3 tablets, 4-6 times a day
Children, 6-12 years: 1 tablet, 4-6 times a day
Children, 3-5 years: half a tablet, 4-6 times a day
Children 1-2 years: one quarter tablet-4-6 times a day.
If ringing in the ears develops, take less. If there are no problems, you can increase the dose a little until the ears start ringing, and then lower it slightly.



The dosage given here is the anti-inflammatory dosage, which is double the normal dosage for reducing pain and lowering fever. The dosage is based on 100 mg of aspirin for each kg of a person's weight each day. For example, a child weighing 25 kilos would take 2500 mg each day, or 1 tablet of 500 mg, 5 times a day (always together with meals or lots of water).

> *CAUTION;* Aspirin tablets for adults usually come in 325 mg (5 grain) or 500 mg (8 grain) tablets. Children's aspirin usually comes in 81 mg. (1 1/4 grain) tablets. Be sure to figure out the dose correctly. Avoid aspirin combined with caffeine or with other painkillers.

The dose of aspirin for your child is_____

CHAPTER **16**

Juvenile Arthritis

Chronic Arthritis in Children

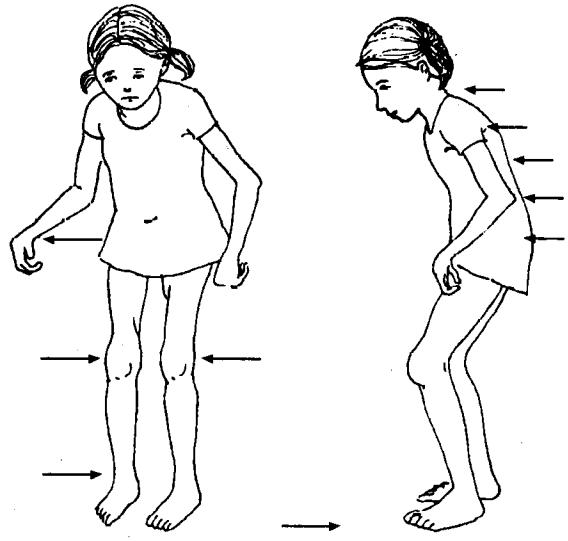
HOW TO RECOGNIZE IT

- The arthritis (joint pain) often begins between the ages of 5 and 10, but may begin in very young children or teenagers.
- Usually it keeps getting worse for several years.
- There are times when the pain and other signs get better, and times when they get worse.
- It affects different children in different ways. It can be mild or very disabling.

Signs

JOINTS THAT MAY BE AFFECTED

First, these joints — Later, these joints



- **Joint pain.** Often begins in the knees, ankles, and wrists. Later it affects the neck, fingers, toes, elbows, and shoulders. Still later, the hips and back may be affected.
- Joints are especially painful and **stiff in the morning** (morning stiffness)



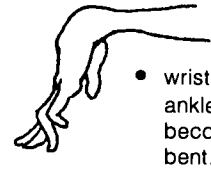
- A child with severe arthritis often sits with his arms and legs bent in the least painful position. Without exercise and good positioning, contractures may form so that he cannot walk or even stand up.



- Children with severe arthritis in the neck and jaw may have a small, short chin.



- The fingers may become very thin and deformed, or thick, with slender tips.



- wrists and ankles may become stiff and bent.

- Contractures may develop in fingers or toes, and with time the bones may fuse (stick together).

- **Fevers and rash** that come and go. (In some children these are the first signs.)
- The knees become large and may turn inward.
- Pain may make it difficult to straighten the knees, hips, and other joints. The cords may tighten, forming contractures, and the bones may gradually become dislocated.

More information about JUVENILE ARTHRITIS

There are three types of juvenile arthritis:

1. **Fever type:** There are times during the day when the child has a high fever, a rash, and feels ill and tired. He looks very sick. The joint pain seems less important, and it begins days or months after the other signs. There may be severe anemia (child looks pale).

2. **Many-joints type:** More than 5 joints with pain. The child hurts a lot, and moves very little. Often severe contractures develop., The child does not grow much, and his sexual development is delayed.

3. **Few joints type:** Fewer than 5 joints affected. It can affect more joints after months or years. If the back is affected, it is more likely that severe arthritis will continue when he is an adult. It may affect the eyes, causing iritis and blindness.



iritis

What causes it?

The exact cause of juvenile arthritis is not known, but it has something to do with the body's 'immune system' (defenses against disease). This begins to attack not only germs, but parts of the body itself. The problem is usually not ***hereditary*** and is not related to climate, diet, or the child's way of life. It is not caused by anything the parents may have done. It cannot spread from one child to another. It does not affect the child's intelligence.

Will the child get worse, or better? What about her future?

The progress of the disease varies a lot. Typically, there are times when the joints become very painful, and times when they hurt less. Often the joint pain and ***disability*** will get worse and worse for several years, then gradually start to improve. Two out of 3 children will stop having active arthritis after 10 years, although the damage already done to the joints may cause some permanent disability. Some children will continue to have arthritis when they are adults, but it is usually milder.

Most children with arthritis will become adults **who walk, work, and have full and happy lives.**

How does it affect the child and her family?

A child with severe arthritis suffers a lot. After a night of being kept awake by the pain, the child may be irritable, sad, and dull. But when the pain is less, she may be friendly and lively.

Since the arthritis often continues to get worse for years, even with all efforts to cure it, both the child and her family may lose hope and stop trying.

Also, the family may not understand how much the child is suffering, because the cause of the pain does not show. (In children's arthritis the joints do not usually get red, as they do in adults.) So the family sometimes calls the child a 'cry-baby' or a trouble-maker. The child may feel abandoned or guilty. The situation is very hard on the whole family.

The family needs the help and support of understanding neighbors, health workers, and, if possible, a rehabilitation worker. They need to understand that by continuing exercises, ***therapy,*** and medicines – often for years – **the child does have hopes of getting better.** If therapy takes the form of games with other children and family members, it may help both her body and spirit.

SECONDARY PROBLEMS

When parts of the body do not get enough movement or exercises, joint contractures are common. With time , the bones may become fused (joined together) or dislocated. Also, the ***muscles*** that straighten the arms and legs become very weak. However, with exercises and with enough movement and good positioning, all these problems can be prevented or made less severe.

Managing juvenile arthritis

The child will need :

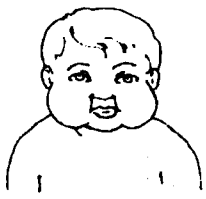
1. **medicine** to relieve the pain and help prevent damage to the joints
2. plenty of **rest,** keeping the body in **good positions**
3. **exercises** and **movement** to prevent contractures and deformities, and to keep the muscles strong
4. **mental, physical, and social activities,** so that the child's life is full and satisfying
5 if necessary, **aids,** and **braces** or **casts** to correct contractures and to help the child to move about.

MEDICINES



Aspirin (acetylsalicylic acid) is usually the safest and best medicine. It not only helps the pain, but also reduces inflammation and damage in the joints. For precautions and doses, see the INFORMATION SHEET on p. 154.

Medicines that generally should NOT be used:



'moon face' and hump of fat on the back of the neck, caused by steroids

Corticosteroids have a strong anti-inflammatory effect, but they are dangerous. Although they quickly reduce the pain, joint destruction continues. Steroids make the child's body less able to fight ***infection,*** stop his growth, and weaken his bones so that they break easily. If the child takes a lot of steroids, his face becomes round and a hump of fat forms on the back of his neck and shoulders. As a rule, **steroid should be used only when the child's life or eyesight is in danger.** Steroid eyedrops at the first signs of iritis can prevent blindness.

Gold salts. Gold combined with sodium and sulfur, in injectable form, sometimes helps when aspirin is not effective. But it is very ***toxic*** (poisonous) and its use should be limited.

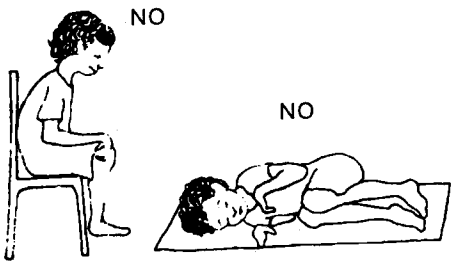
Indomethacin (Indocin), phenylbutazone, and related medicines are so ***toxic*** that they should not be given to children.



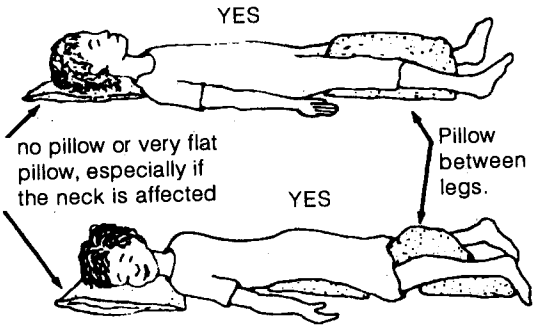
WARNING: We mention corticosteroids, indomethacin, and phenylbutazone because many doctors prescribe them unnecessarily, putting the health or life of the child in danger. If a doctor prescribes one of these medicines for a child, get advice from other doctors before using it.

REST AND POSITION

Children with arthritis need a lot of rest. They tire easily, and should have a chance to rest often. **Help the child to be in positions that keep the arms, wrists,hips, and legs as straight as possible.**



In these positions, contractures develop more easily.



In these positions, contractures are less likely to develop.

Although it may be hurt more, it is better for the child to lie on her back or stomach, not on her side with her legs bent.

When pain is worst, alternate rest with legs straight and slightly bent.

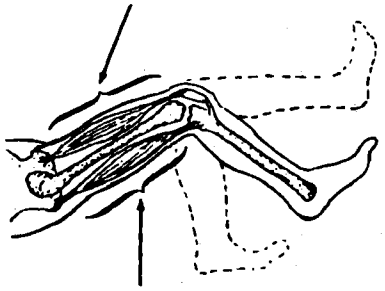
Rest and sleep with the arms and legs as straight as possible. Use pillows only in a way that gently helps the joints straighten more. Let the legs slowly straighten under their own weight.

EXERCISES AND MOVEMENT

Our goal is to prevent contractures and dislocations, and to maintain the fullest possible range of motion for the body. So exercises are needed to **strengthen the muscles that straighten the joints.**

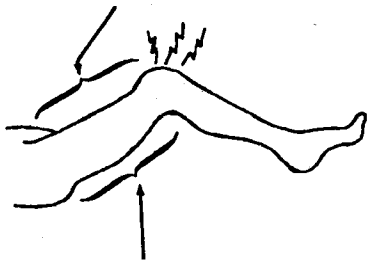
HOW PAIN CAUSES CONTRACTURES

When these muscles are tightened, they straighten the knee,



and these muscles bend it.

Because it hurts to straighten the knee, the child with arthritis does not use these muscles much. So they become very weak.



But these muscles stay tightened to keep the knee bent and guard against pain. So they stay stronger.

Since the muscles on top are weaker than those below, the uneven muscle strength keeps bending the leg more and more, even during sleep.



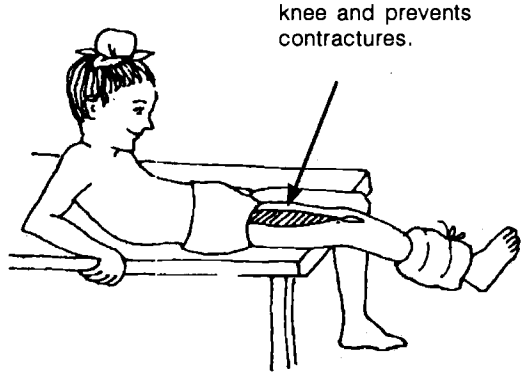
Note: This kind of uneven muscle strength is called ***muscle imbalance.***

Because contractures from arthritis result mainly from unequal muscle strength, it is important that the child **do all exercises and activities in ways that will strengthen the weak muscles that straighten the joints,** not the muscles that bend them. For example:

Do exercises that work this muscle.

YES

This is the muscle that straightens the knee and prevents contractures.

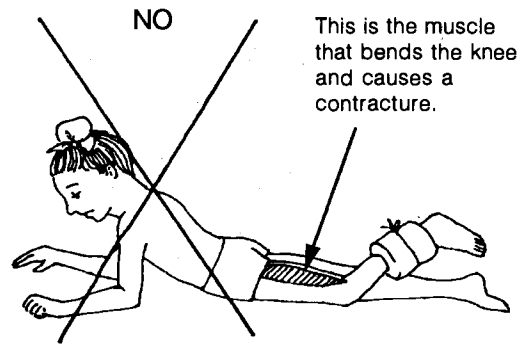


STRENGTHEN MUSCLES THAT STRAIGHTEN THE JOINT.

But do not do exercises that work this muscle.

NO

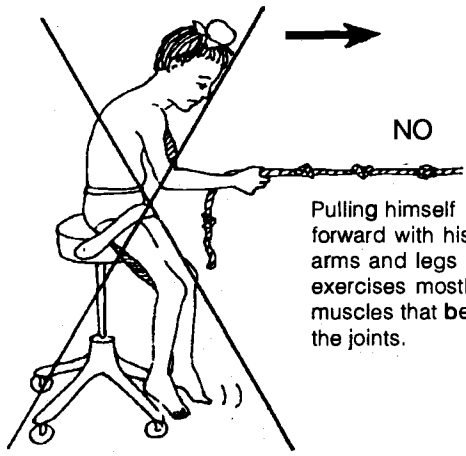
This is the muscle that bends the knee and causes a contracture.



DO NOT STRENGTHEN MUSCLES THAT BEND THE JOINT.

Follow this same logic with all exercises and activities. And **look for ways to make the exercises useful and fun.**

For example, Kuldeep has arthritis and can no longer walk by himself or straighten his arms and legs completely. As a way of moving himself about and getting some exercise, He can sit on a chair with ***casters,*** as shown here. But he should be careful to move in a way that helps prevent contractures.



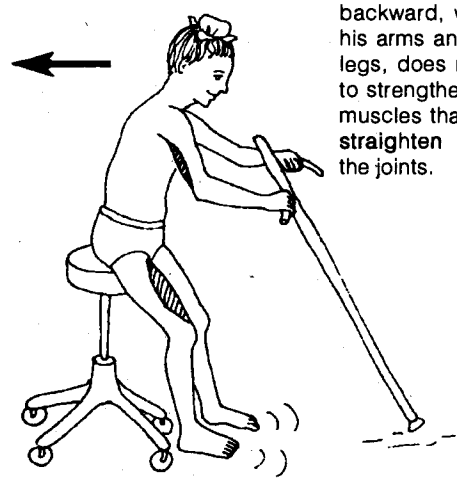
NO

Pulling himself forward with his arms and legs exercises mostly the muscles that **bend** the joints.

This can make contractures worse.

YES

Pushing himself backward, with his arms and legs, does more to strengthen the muscles that **straighten** the joints.



This helps prevent contractures.

Helping the child to strengthen the right muscles

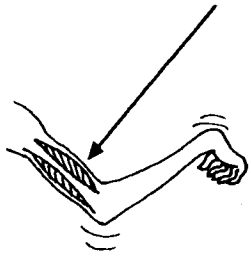
One problem with exercises is that, when either you or the child try to straighten a joint, pain – or the fear of pain–can cause her to tighten the muscles that bend it. For example:

If you pull like this, the muscles that bend the elbow will pull against you–and get stronger.



The muscles that straighten the elbow will not be used – and will get weaker.

Even if the child herself tries to straighten her elbow, the pain will cause the stronger, bending muscles to tighten.



As a result, these exercises may strengthen the bending muscles instead of the weaker straightening muscles. This means that these exercises can actually make contractures get worse!

EXERCISES WITHOUT MOTION

So it is important that the child learn to do exercises that strengthen the muscles that pull against contractures, not those that make them worse. This will be easiest and least painful if she does **exercises without motion.**

First help her to learn which muscles move parts of her body in different directions.

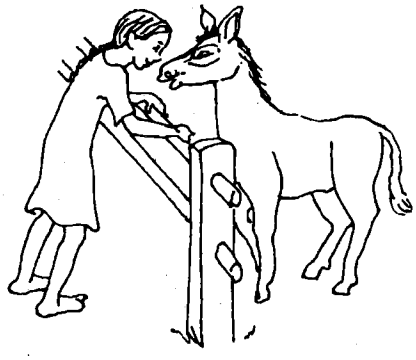


Have her exercise these ,muscles by relaxing and tightening them, **without moving her arm.**

Then help her find interesting ways to strengthen the muscles that need it without moving them. For example,. she can lean on a fence like this.

Everyday she can step a little farther back from the fence to take more weight on her arms.

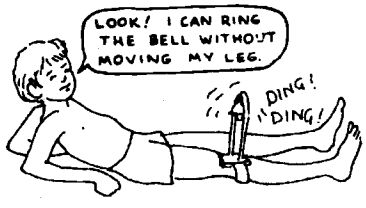
Notice that this exercise also strengthens her knee-straightening muscles and helps stretch her heel cords, wrists, hips, back, and neck, in order to look in the eye.



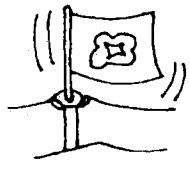
***Note:* We have shown these exercises in a girl who already has contractures. But it is best to start them before contractures begin.**

You can figure out similar exercises without motion for all the weak muscles that need strengthening to help prevent or correct contractures.

For example, to strengthen the knee-straightening muscles, the child can lie on her back with her leg as straight as possible. Have her tighten the muscles on top of her thigh (without tightening those underneath) and count to 25. Then relax and repeat 10 times a day. Again, look for ways to make it more fun.



Tightening this muscle pulls the kneecap and rings the bell.



You can strap a small bell or flag to the leg, so that it will ring or move when the knee bone moves.

Progression of exercises for the child with an ARTHRITIC KNEE

(Arthritis often starts in the knee and later affects other joints.)

CONCEPTS:

1. Strengthen the muscles that straighten the knee (without strengthening those that bend it).
2. Do not move the knee when doing exercises.
3. Keep changing the position in which you do the exercise, and add weights to make the exercises harder as the child's strength increases.

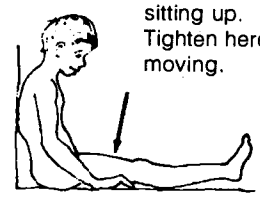
First exercise: leg on ground

First do the exercise without motion lying down.



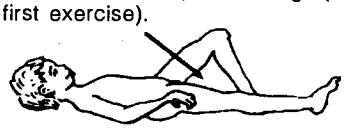
Tighten here without moving and count to 25. Relax and repeat 10 times. Do it 3 or 4 times a day.

After a few days, do it sitting up. Tighten here without moving.

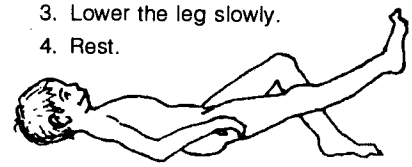


Second exercise: straight leg raise

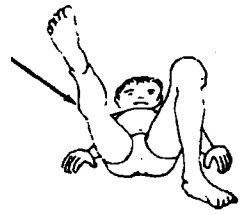
1. With the leg straight, tighten the muscles on top of the thigh (as in the first exercise).



2. Then lift the leg without bending the knee, and slowly count to 5 or 10.
3. Lower the leg slowly.
4. Rest.



When you lift the leg, be sure that the knee points up or slightly out to the side.



Do not let knee bend at all.(If the knee bends even a little when you lift the leg, it means that the muscles here are still too weak. Go back to first exercise.)



When the child can do this exercises lying down **without bending his knee,** begin putting weights on his leg:

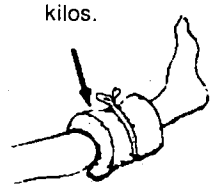
first 1/2 kilo

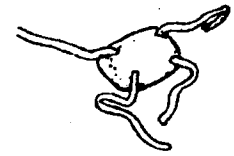


Gradually increase the weight to 1 kilo.



and 1 1/2 kilos.

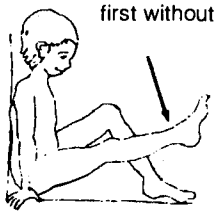




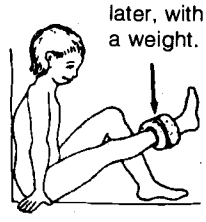
For the weight, you can use a small bag full of sand.

After a few days, have him do the same exercise sitting up:*

first without a weight.



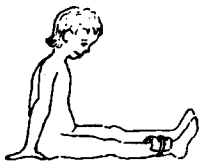
later, with a weight.



Again, gradually increase the weight. Begin with half a kilo, and build up to 5 kilos. But do not increase the weight until the child can do the exercise at the first weight without bending his knee.

CAUTION: Do not do this sitting exercise if the child has arthritis in the hip, or hip contractures. It uses the hip-bending muscles that will make the contractures worse.

When the child can do the exercise at 2 kilos without bending her knee, she can begin doing the following variation. Keep the leg raised the whole time.



1. Tighten the muscle on top of the thigh.



2. Lift the leg, keeping it straight.



3. Move the leg to the side and turn it outward.



4. Move the leg back in and turn it inward.



5. Lower the leg and relax.

IMPORTANT: **If there is also arthritis in the hip, or hip contractures, do these exercises lying down, not sitting up.**

Third exercise: knee slightly bent

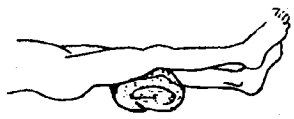
1. Lie down with a rolled towel or blanket under the knee.



2. Turn the leg out to the side.



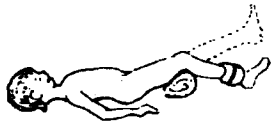
3. Lift the foot and slowly count to 5 or 10.



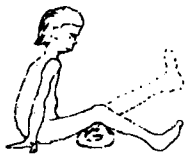
4. Lower it slowly.
5. Rest.
6. Repeat the exercise 10 to 30 times.

Make sure that only the foot is raised, not the thigh, and that the knee is lifted as straight as possible.

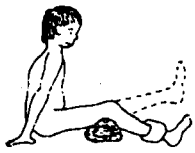
As the child gains strength, continue with the same series of steps as for the second exercise.



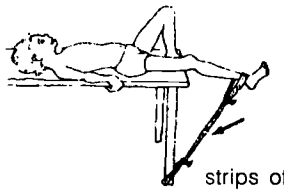
1. Lying down, lift the foot with a weight on it. Build weight up slowly to 5 kilos.



2. Sitting up, lift the foot without a weight.



3. Sitting up, lift the foot with a weight. (Build up to 5 kilos.)



strips of inner tube (or use sandbag)

If arthritis or contractures have begun in his hip, it is best to do the exercise lying down with the hip as straight as possible (nothing under the knee).

Do these 2 exercises only if there is no danger of hip contractures.

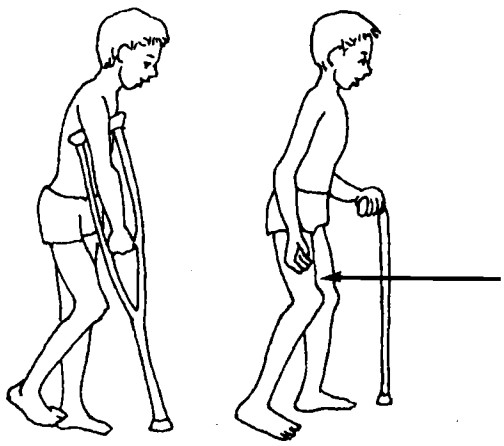
To strengthen the muscles, continue the exercise until the child can no longer hold the leg straight or it begins to shake slightly. The more often the child does these exercises the faster the muscles will get stronger. These exercises can be done even when the joint is swollen and painful. However, if the joint hurts more during or after the exercise, use less weight and repeat fewer times.

Exercising ARTHRITIC KNEE through daily activities

WALKING. Walking is one of the best exercises for strengthening the thigh – if the child puts some weight on the leg.

For arthritis, try to **use canes, not crutches. A crutch can cause contractures.**

NO YES



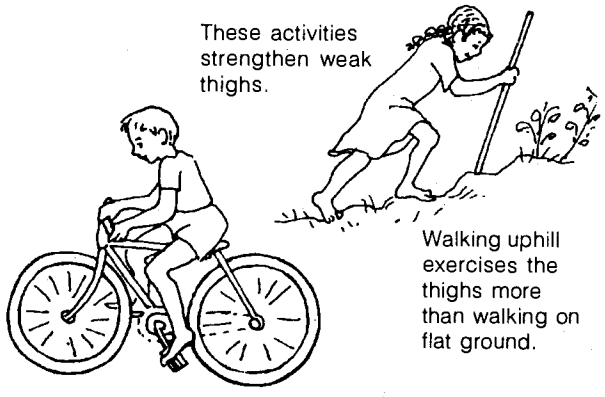
A cane helps strengthen weak muscles and revent contractures.

If he uses a cane, he must put some weight on the leg. This strengthens the muscles that strengthens the leg.

WARNING : If a child uses a crutch and does not step down with his leg, this strengthens only the muscles that bend the leg.

During the times when the child's arthritis is less painful, she should be active. It is fine for her to run, ride a bicycle, or take long walks – as long as this does not cause much joint pain.

After the child can walk fairly well without aids, a good exercise is walking on the heels. (If the arthritis also affects the ankles, this may not be possible. But try.)



These activities strengthen weak thighs.

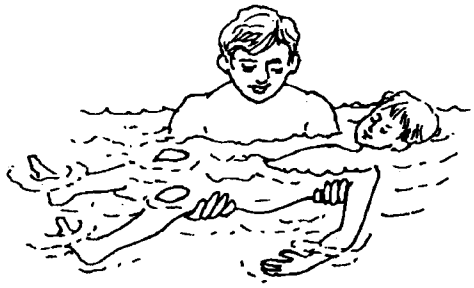
Walking uphill exercises the thighs more than walking on flat ground.



Floating and play in water also is good exercise. The water holds up the body and allows movement of the arms and legs without weight, yet against the gentle resistance of the water.

SWIMMING: Swimming is one of the best exercises for a person with arthritis.





Range-of-motion exercises for children with arthritis

For a child with arthritis, it is important that **every day he move his body, arms, and legs through as full a range of motion as possible**

Note: **Range-of-motion exercises for different joints are described in Chapter 43. Here we discuss ways to make them easier for children with arthritis.**

But this is not always easy. Pain and stiffness make straightening of joints difficult. So before starting to exercise, take steps to calm the pain and relax the tense muscles. **Aspirin** helps do this. Take it half an hour before beginning exercise (or before getting up to help morning stiffness.

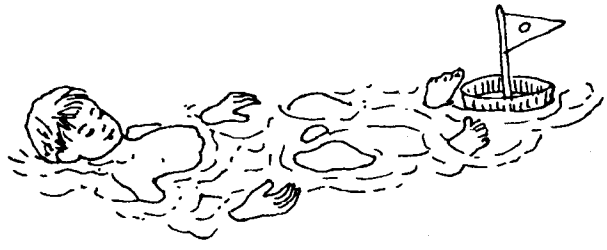
Heat helps relax muscles and calm pain. Suggestion for applying hot soaks and hot wax are on p. 152. If many joints are painful it helps to lie in warm water (a little warmer than body temperature).

If possible, get or make a tub large enough for the child to lie straight and to stretch his arms and legs in all directions.

Warm water not only helps calm pain, but gently lifts and takes the weight off body parts. This makes motion easier. Support the child only as much as needed so that his arms and legs are loose and held up by the water. Ask him to relax completely. Let him begin to move his arms and legs. The more he relaxes, the more they will straighten as he moves.



Ideas for making tubs or water pits heated by the sun are on p.153



Find ways for the child to play in the water. This will help him forget his pain and make straightening the joints easier.

In moments when she has his leg or arm most straight,ask him to hold that position a moment without bending.

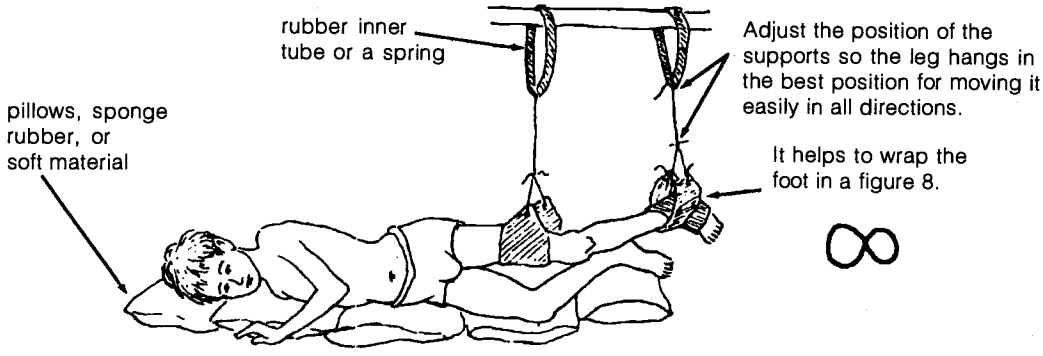
This way, little by little, he will find he can straighten his joints more and more.



'Floating-in-air' devices for relaxing and moving painful joints

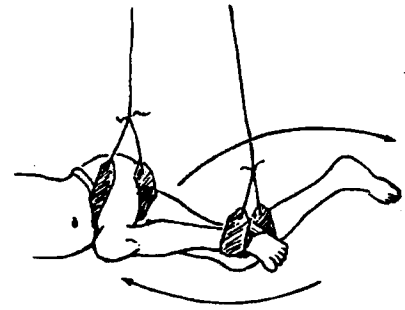
The best way for relaxing and reducing weight to exercise arthritic joints is to float in warm water. When this is not possible, after applying hot soaks (see p.152), the leg or arm can be hung in a simple device – loosely, as if floating in water.

'FLOATING' AN ARTHRITIC LEG



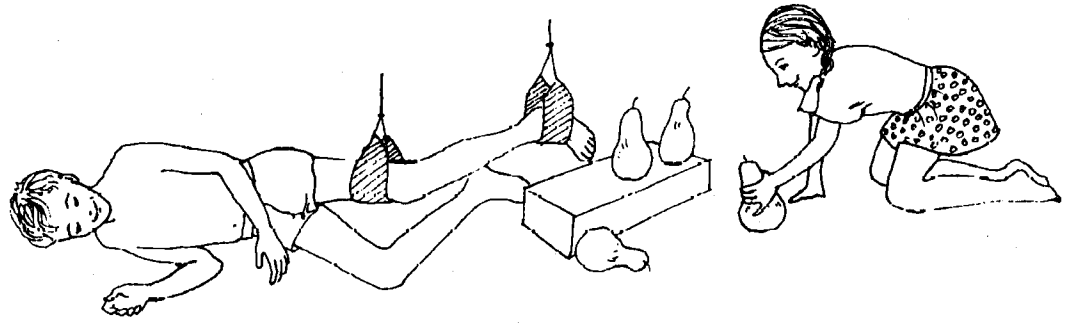
After hanging the limb, wait until the child relaxes, then have him swing it gently this way and that.

Let the leg move with its own weight as in a swing. Increase the swinging until the knee and hip bend and straighten completely (or as much as possible).



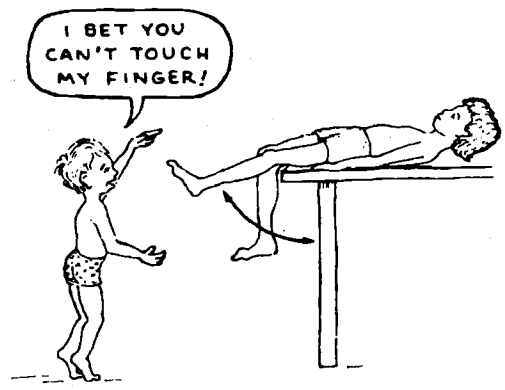
Look for ways to turn the exercise into a game.

For example, the child might knock gourds or blocks down while another child tries quickly to set them up again, and see who wins.

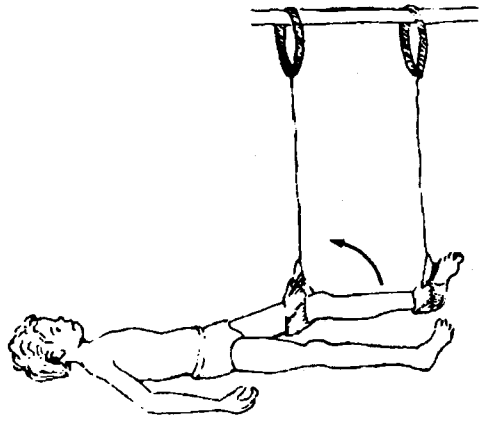


The gourds can be put farther and farther away so that he has to stretch more each time to knock them down. When his leg is most stretched, ask him to hold it that way a moment before letting it bend.

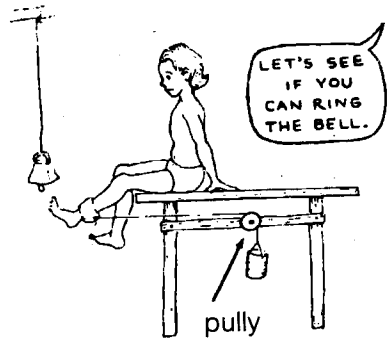
Also have the child do exercises lying on his back and swinging his leg outward (to one side). This helps prevent knock-knee contractures.



This child can also swing her leg while sitting or lying on a table edge. Encourage her to swing the leg as far up and back as possible. Turn it into a game.



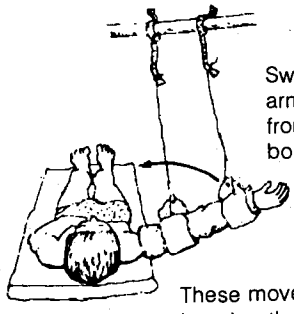
A device like this helps strengthen the muscles that straighten the knee. This way works better than a weight tied to the ankle because the pull continues even when the knee is bent.



Put stones or pieces of metal in an old can. Use only as much weight as will let the child straighten her knee completely. As leg becomes stronger, add more weight.

Movement of the arms. This is done much like the legs:

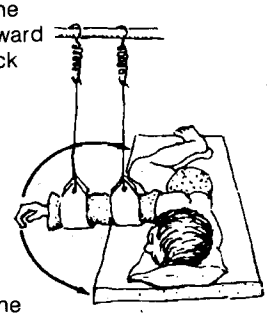
LYING FACE UP



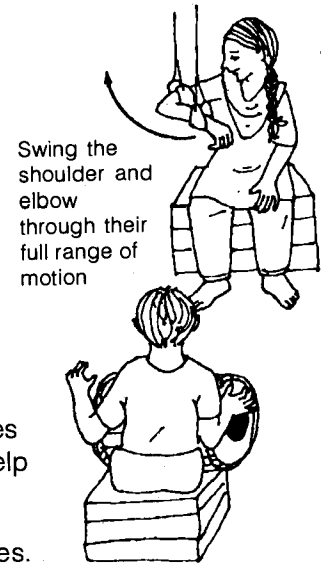
Swing the arm away from the body.

LYING ON THE SIDE

Swing the arm forward and back



AND SITTING



Swing the shoulder and elbow through their full range of motion

These movements can be done keeping the hot soaks on the arm.

Encourage the child to move her limb in a rhythmic manner – perhaps to music. Try to help her forget the pain. If she becomes interested in something else – a game or the music – this will help reduce the tightness of her muscles.

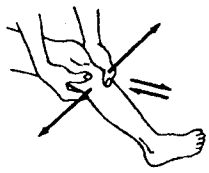
Look for ways to do these movements as part of daily activities.

CORRECTING CONTRACTURES CAUSED BY ARTHRITIS

For general information on the **cause, prevention, and correction of contractures,** see Chapter 8. **Range-of-motion and strengthening exercises** will help prevent or correct early contractures (see Chapter 43). For severe contractures, **stretching aids or casts** may be needed (see Chapter 60). However, when using casts or other aids to straighten contractures,**it is very important to continue exercises without motion** to strengthen the muscles that straighten the limb.

PRECAUTIONS FOR CASTING AN ARTHRITIC LIMB

1. First examine the joint for signs of dislocation. Try moving the bones forward and backward and from side to side.

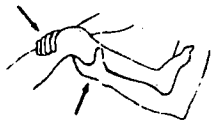


CAUTION: **If the joint is partly dislocated or very loose, it is best not to use casts or stretching devices, as these can increase the dislocation.** It is better to continue with the exercises, taking care not to force the joint.

2. If there are no signs of dislocation, little by little straighten the joint as far as is possible without causing much pain.

CAUTION:" **Do not pull like this, or you may dislocate the joint.**

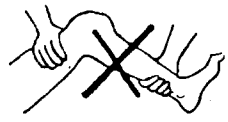
LIKE THIS

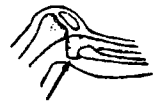


Lift with your hand behind the knee to keep the bones correctly in place, like this.



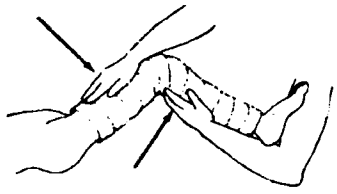
NOT LIKE THIS





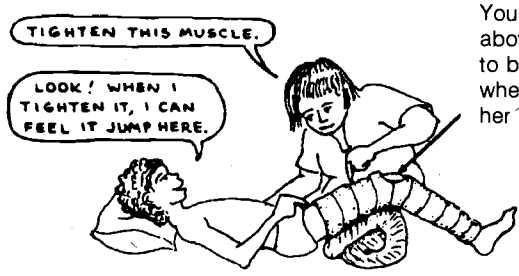
dislocated joint

3. With the joint as straight as you can get it without too much pain, carefully cast the leg (see p.684).



Until the cast dries, apply steady pressure here so that the bones keep their right locations and the joint stays straightened.

4. As long as the cast is in place, do without-motion exercises several times a day. This helps keep the straightening muscles strong.



You can cut a hole above the kneecap to be sure it moves when she tightens her muscles.

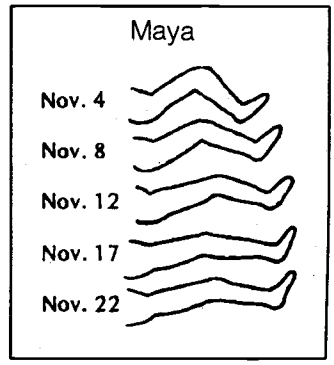
5. Every 2 days remove the cast, apply heat and do range-of-motion exercises, bending and straightening the leg little by little. Then gently stretch the leg a little more, and put on another cast.



(*IMPORTANT*:It is best to replace the cast completely rather than to use wedges with the same cast, because of the risk of dislocation.)

6. Continue straightening the leg with new casts every 2 days until it is completely straight or does not straighten more.

Keep a record of the progress like this (see Chapter 5). This way you can tell when the leg is no longer getting straighter and it is time to stop using casts.



Homemade aids for stretching joints

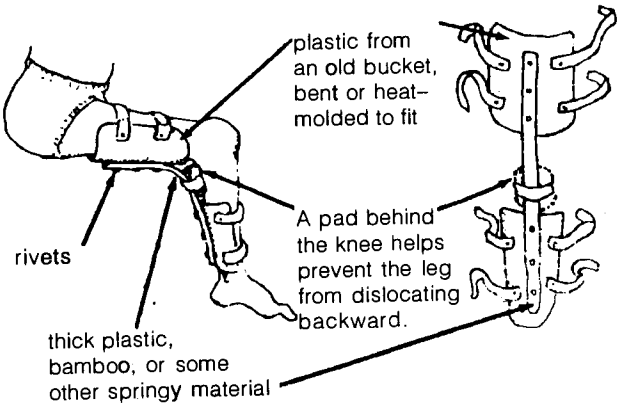
Because daily movement of joints is so important with arthritis, casts should be avoided whenever possible. So try to figure out other ways to correct contractures. Use whatever materials you can find, such as plastic, bamboo, and inner tubes.

These are a few of the examples of aids invented in a Mexican village for a girl with arthritis.

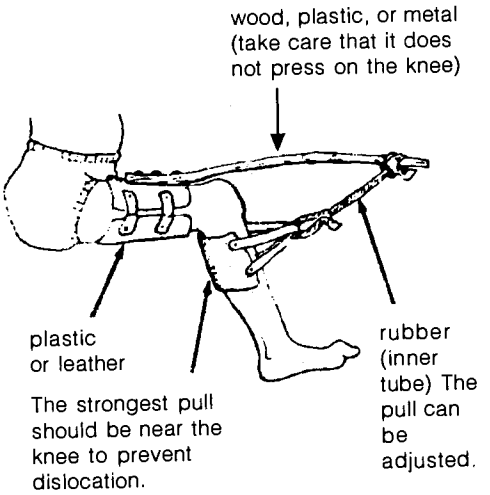
CAUTION: **Make sure that the aids pull in a way that does not cause dislocations**

KNEE

METHOD 1:

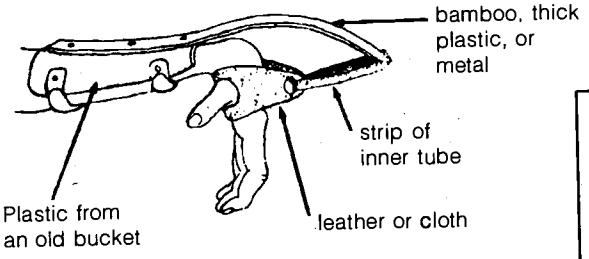


METHOD 2:

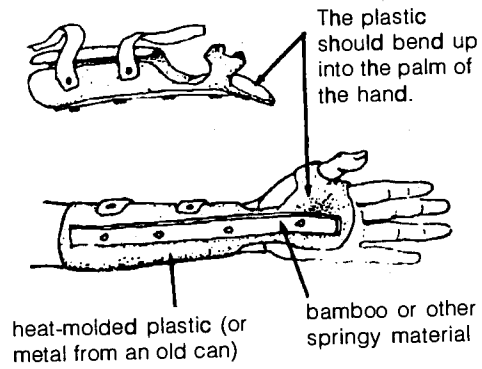


WRIST

Over-the-hand support



Under-the-hand support



Note: The behind-the-knee aid usually works the best. It is steadier and so causes less muscle tightening. Because it holds the leg more firmly, it is less likely to cause dislocations. It is also more comfortable and less awkward.

PRECAUTIONS in the use of aids for stretching contractures:

- They should be made in a way that will prevent dislocations. When using,**check often for early signs of dislocation.**
- The aids should not pull so much that they cause pain and defensive muscle tightening.
- Use them during most of the day and at night (about 20 or every 24 hours)
- Remove them 2 or 3 times a day in order to do exercises.
- Also do exercises without motion with the aids in place.
- Take care that the aid does not stop blood flow or press on nerves. If the hand or foot becomes cool, changes color, begins to hurt or becomes numb – remove the aid, and make the needed adjustments.

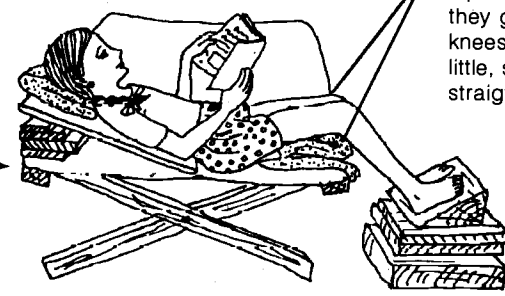
For other aids and devices for straightening contractures, see Chapter 60.

Correcting contractures of arthritic hips

Look for ways that the child can relax with her head as straight as possible. If she also has contractures in her knees, she can lie like this.

The child will relax and straighten her body more easily if she can play or read

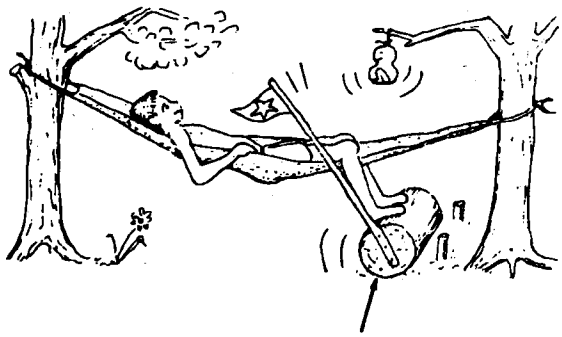
Place supports or cushions behind her back and head, but just enough so that she has to straighten herself some. As her hips and neck gradually straighten, keep lowering her back and head little by little.



Give just enough support under her knees and feet to keep her hips and knees stretched. As they gradually relax, lower her knees and raise her feet little by little, so that her hips and knees straighten.

In the morning, she may be stiff and bent, and will need help to straighten like this every day – or several times a day.

If possible, also have her lie on her belly.



log, barrel, or bucket

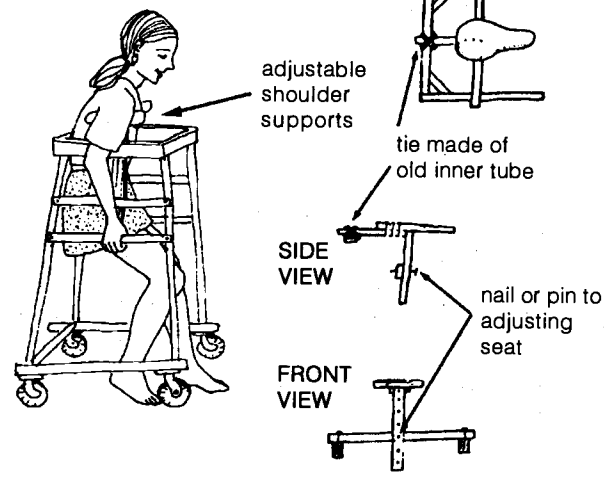
Think of games or exercises in which the child will stretch his hips and knees. In this example, the boy rolls the log to lift the flag and hit the gourd. This helps strengthen the straightening muscles of his legs.

As the child's back,hips, and knees straighten more and he gains strength, the hammock can be stretched more tightly and a heavier weight put on the top of the stick, where the flag is.

A homemade walker similar to this can help a child with hip contractures begin to walk. It also provides exercise for the straightening muscles of both the arms and legs.

As the child's hips and knees straighten more and more, the crutches and seat can be raised.

It is best if she walks backward ("Pretend you're a crab!"). This way she will strengthen the straightening muscles in her legs. Walking forward would strengthen more the muscles that bend the legs, and this could increase contractures.



LEARNING TO MOVE AND TO SMILE – The story of Teresa

Teresa has had juvenile arthritis since age 7. When her mother first brought her to PROJIMO from a distant village at age 14, her body had stiffened into the shape of a chair. Her eyes were the only parts of her body she could move. Her joints hurt her so much that she spent every night crying. Years before, a doctor had prescribed aspirin for her pain. But the aspirin began to give her severe stomach pain, so she stopped taking it.

Once Teresa was a cheerful, active little girl. She had completed 3 years of school. Now she was sad and felt hopeless. She would cry out with pain each morning when her father carefully lifted her out of bed and sat her in a chair. She rarely spoke and never smiled.

When Teresa arrived at PROJIMO she had severe contractures of her wrists, fingers, elbows, hips, knees, ankles, and feet. The rehabilitation team had her start using aspirin again, but with care that she take it with meals, lots of water, and an antacid. They then began a long, slow process of therapy, part of which we show in the following photos.



To help correct her wrist contractures, visiting therapists made these splints for her out of costly plastic.



However, to the therapists 'surprise, they found out that these low-cost splints made by villagers from a plastic bucket worked better (see p.671).



Every day the team spent several hours with Teresa gently doing range-of-motion, stretching, and strengthening exercises. Here a visiting physical therapist teaches a village worker how to help Teresa increase movement in her stiff neck and back.

They also made leg splints out of plastic buckets and strips of rubber tire tube.





When Teresa could move her joints some, the team made her an adjustable walker. It had shoulder supports and a saddle seat that could be raised as her legs straightened. She learned to walk by pushing herself backward. This strengthened the muscles that straighten her legs.

Teresa was improving steadily. She began to talk, smile, and to take interest in things. An older brother came to visit for a few weeks. He learned about her exercises and therapy so he could help her when they returned to their village.

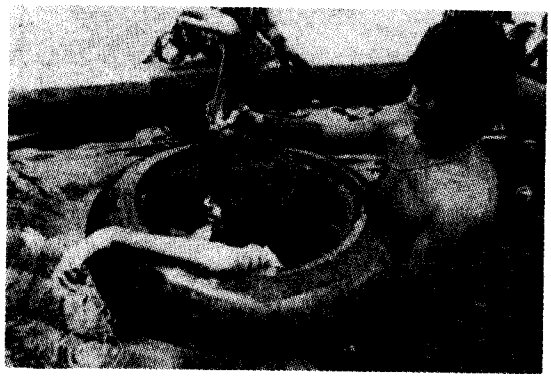
Unfortunately, soon after Teresa went home she became ill with dengue (break bone fever) and nearly died. Her family stopped both exercises and medicines. When she returned to PROJIMO 6 weeks later, she was as stiff and bent as when she first came. She was so depressed she spoke to no one. The team began her rehabilitation all over again.



This time they straightened her legs and arms with plaster casts (see Chapter 60). They changed the casts every 2 days. With each cast change her joints were exercised.



Finally, with the casts, Teresa's knees and wrists became fairly straight. She now had some hand movement and could play in the playground.



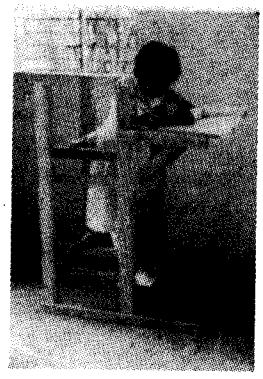
Exercise in the therapy pool at PROJIMO was fun and greatly improved her movement.



Kicking balls with other disabled children helped Teresa strengthen muscles that straighten legs.



Village children help her with activities to use her hands. Here she weaves a basket.



When her legs were stronger, the team made an adjustable standing frame for her.



Later Teresa began to walk using a homemade walker with wood wheel. She wore leg braces for support.

As Teresa's legs and arms straightened, her neck bent forward more and more. She could not lift her chin from her chest. The village workers made her a head support, attached to a firm cloth around her chest. Over a period of months, the support gently brought up her head.







Teresa is now able to walk with crutches. Through daily work she gets much of the same therapy she gets doing her exercises.



She also continues with her daily exercises to straighten and strengthen her arms and legs.



Sewing together with her friends helps Teresa improve the use of her hands. She is also gaining skills with her therapy. (5 photos by Richard Parker)



At home, Teresa now helps care for her younger brothers and sisters. She and her family share the household tasks. Before, others had to take care of her.

(photo by Andy Brown)

CHAPTER 17

Rheumatic Fever

Rheumatic fever is a serious illness with **joint pain** and **fever.** It usually lasts about 6 weeks but may last up to 6 months (or rarely more). Then the joint pain usually goes away completely. But **heart damage,** if it has occurred may be permanent or become ***disabling*** (shortness of breath; sickly child).

CAUSES

Rheumatic fever usually results **after a sore throat** caused by bacteria called 'streptococcus'. (The rheumatic fever is somewhat like an allergic reaction.) A 'strep throat' often starts suddenly with throat pain and fever and **without** signs of a cold. Two to three weeks after an episode of sore throat, rheumatic fever may start with fever and joint pains. However, all sore throats do not lead to rheumatic fever. All streptococal throats also do not lead to rheumatic fever. Rheumatic fever is most common where epidemics of strep throat are common–**in crowded communities with poor hygiene.**

PREVENTION

Rheumatic fever can often be prevented by giving penicillin to children who have signs of a strep throat. Keep giving penicillin for at least 3 days after all signs disappear. Long-term prevention involves improving hygiene and living conditions (a fairer society).

CAUTION: Most sore throats in children are not 'strep', but are caused by the common cold; these should **not** be treated with penicillin, or any other antibiotic and never injections (see p. 20). Typically, a **strep throat is quite painful and starts suddenly, with high fever,** and **without** a stuffy nose or other signs of a cold.

SIGNS OF THE TYPICAL CASE

- Child between the ages 5 to 15
- Began 1–3 weeks after the child had a severe sore throat
- Fever- Mild to very high. Child quite sick
- Joint pain. Pain often starts in one or more of the larger joints (especially wrists and ankles). Then it changes to other joints, often knees and elbows. The painful joints may swell and become red and hot.



- Child gets well in about 6 weeks to 3 months, but may get the same illness again after another sore throat.

OTHER SIGNS (not always present)

- Reddish curved lines on skin
- Lumps (the size of peas) under the skin over or near the joints
- **Jerky movements** of hands, face and limbs while the child is conscious. These are not fits and disappear during sleep.
- Heart problems. You may hear a 'murmur' if you put your ear over the child's chest. Instead of the typical 'lub-dub...lub-dub' of the heartbeat, you will hear a soft, long 'whoosh' for one of the sounds: 'whoosh-dub'. The 'whoosh' sound means a valve to the heart has been damaged so that it does not close completely. In extreme cases this can lead to heart failure (see ***Where There Is No Doctor, p. 459)***
- The child may become breathless while walking, or even at rest in severe cases.
- Nosebleed, belly pain, chest pain, or signs of pneumonia occur in only a few cases.

Treatment

- If you think a child might have rheumatic fever, get medical advice quickly. Early treatment may help prevent heart damage. (After fever and joint pain have begun, treatment does not seem to shorten the length of the illness.)
- Normally, penicillin is given, either by mouth or in an injection form. For children who are allergic to penicillin, erythromycin is given. (For ***cautions*** in the use of penicillin, see ***Where There Is No Doctor,*** p.493.)
- Aspirin is also given in high dosages. An information sheet with the dosage and precautions for taking aspirin is on p. 154. Continue giving aspirin until a few days after all signs are gone.
- Apply heat or cold packs to painful joints to help reduce pain and swelling (see p. 152).
- Do full range-of-motion exercises of painful joints gently every day (see Chapter 43).
- Do 'exercises without motion' to maintain strength (see p. 160).
- The child should stay in bed or rest quietly most of the time until all signs are gone (about 6 weeks). Then he can begin activities little by little.

TREATMENT OF RHEUMATIC FEVER

Name of medicine	Age	Dose	When to take
Pencillin G or V (by mouth)	up to 3 years over 3 (includes adults)	125 mg. 250 mg.	4 times a day for 10 days.
— OR —			
Benzathine penicillin (by injection)	up to 3 years over 3 (includes adults)	600,000 units 1,200,000 units	single injection (Give one-half in each butt.)
— OR —			
Procaine penicillin (by injection)	up to 3 years over 3 (includes adults)	600,000 units 1,200,000 units	inject one-half into each butt muscle once a day for 10 days.
For persons allergic to penicillin give:			
Erythromycin (by mouth)	up to 3 years over 3 (includes adults)	125 mg. 250 mg.	4 times a day for 10 days.

NOTE: Whenever possible, it is safer to give children medicine by mouth than by injection. For precautions in giving medicines to children, see p. 278

PREVENTION of repeat attacks

Persons who have once had rheumatic fever have a risk of getting it again. For these persons, take care to treat any sore throat quickly with penicillin. If the person shows signs of heart damage (murmur) with the first attack, there is a high risk of further damage with repeat attacks. These persons would be wise to take long acting penicillin every month until they are 18 years of age. In some persons whose heart damage is severe, Benzathine penicillin is given as long as they live. **Long-term prevention is especially important in persons who already have serious rheumatic heart damage.**

PREVENTIVE DOSAGES:

- 1 injection of 1.2 million units of benzathine penicillin G, once a month,
- or 1 tablet of 500 mg. of sulfadiazine 2 times a day,
- or 1 tablet of 125 mg. of potassium penicillin G, 2 times a day with an empty stomach.
- For children allergic to penicillin, give 1 tablet of 100 mg. of erythromycin, 2 times a day.

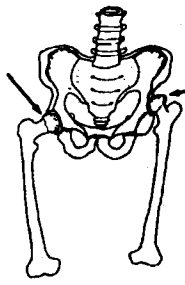
Before using these medicines, read the precautions. See the GREEN PAGES of *Where There Is No Doctor.*

CHAPTER **18**

Hip Problems

DISLOCATED HIPS

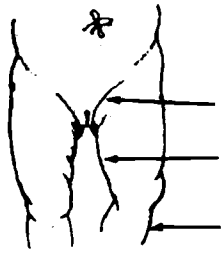
A hip is *dislocated* when the thigh bone is out of its socket at the hip. Some babies are born with one or both hips already dislocated. This is more common in girls. Sometimes these babies have no other problem. With early treatment, the problem can often be corrected easily, and the child will not be *disabled* or have a limp.



NORMAL HIP: The round head of the thigh bone is inside the hip socket.

DISLOCATED HIP: The head of the thigh bone often lies above the socket.

For this reason it is important to **examine all babies when they are 10 days old** to see whether they have dislocated hips.



1. Compare the 2 legs. If one hip is dislocated, that side may show these signs:
   - the upper leg partly covers this part of the body
   - there are fewer skin folds
   - the leg may seem shorter, or turn out at a strange angle

2. Hold both legs with the knees bent, like this,



and open them wide, like this.



If one leg cannot be opened out wide or makes a jump or click when you open it wide, the hip is dislocated.

3. To test a slightly older child, bend the knees and compare their height.



If one knee is lower, the hip on that side is probably dislocated.

Treatment

Keep the baby with his knees high and wide apart. To do this,

- use more thicknesses of diapers (nappies) like this,



- or pin his legs like this (when the baby sleeps),



- or carry the baby like this.



In places where babies are traditionally carried with their legs spread on the woman's hips or back, usually no other treatment is necessary.

Dislocated hips with other orthopedic problems

Children with the *disabilities* listed here often are **born with dislocated hips.** Therefore, it is ***essential*** to examine these children carefully a few days after birth, to make sure there are no dislocations.

- Down syndrome
- spina bifida
- arthrogryposis
- cerebral palsy
- club feet

CP

Many (but not all) dislocated hips can be corrected in the ways we described on page 175. Keeping the legs wide apart during the first months of the child's life helps to improve the shape of the socket.

If it is difficult to keep the legs apart, you may need to use casts or make special braces.

The casts should be used for 2 to 4 months or longer, depending on the child's age (longer for older children) and the amount of the deformity. (Use a cloth or bottle to catch the baby's urine, so it does not run inside the cast.)

CAST

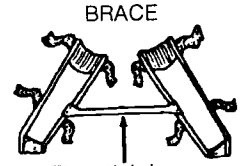


bottle to catch urine

Not all dislocations can be corrected in these ways. Some need surgery, and in some cases the hip is so deformed that the dislocation cannot be corrected, even with surgery. If the child's legs appear short or deformed despite initial treatment his hip may still be dislocated. A specialist's opinion should then be sought.

With spina bifida, if one hip is dislocated, surgery may help. But if both hips are dislocated, hip surgery usually will not help the child to walk any better. (See p. 201)

BRACE



The stick here helps to keep the legs apart.

Dislocated hips can also occur **after the child is born,** either from an accident or as a complication of some other disease like **tuberculosis** or disability especially **polio** (due to weakness in the muscles and cords that hold the hip joint together) or **cerebral palsy** (due to spasticity and contractures). If the dislocation is because of T.B, in addition to treating the hip anti-tubercular treatment should be taken to prevent further destruction of hip. Plaster casts may be necessary to keep the hips relocated.

DISLOCATED HIP



The spasticity and contracture of this muscle cause dislocation of the hip.

CP

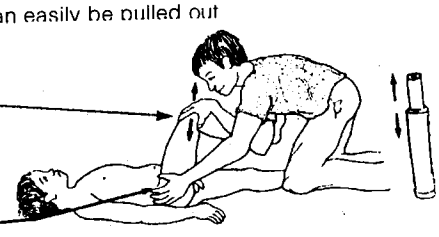
legs crossed like scissors

THE TELESCOPE TEST

To find out if the hip is dislocated or can easily be pulled out of joint, place the child on his back.

Pull up on his knee, and then push it down, like this.

At the same time, feel his hip with your other hand, like this.



If the thigh bone moves in and out like a telescope, the hip is probably dislocated.

Dislocations that are complications of polio or cerebral palsy can seldom be corrected without surgery. **But often it is better not to operate,** because the operations do not always turn out well, and the children who have the possibility of walking will walk in spite of the dislocated hips.

HIPS PROBLEMS DUE TO DESTRUCTION OR SLIPPING OF THE CAP OF THE THIGH BONE

There are 2 different hip problems that occur most often in very active children, usually boys.

1. **Destruction** of the cap or 'growth center' on the 'head of the thigh bone is called **Legg-Perthes disease.** It usually begins **between 4 and 8 years of age.** It occurs in one of every 300 to 600 boys.

2. **Slipping** of the cap on the head of the thigh bone is less common. It happens, suddenly or little by little, usually between **11 and 16 years of age** (when the child is growing fast).

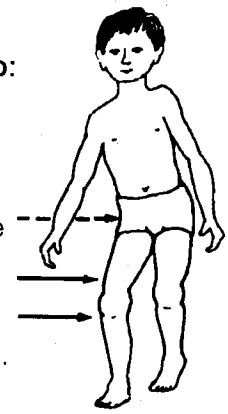
The cause in both cases is often unknown but may be related to an injury caused from jumping or falling.

Destruction of the growth center results from a temporary loss of its blood supply, which results in death of the bone.

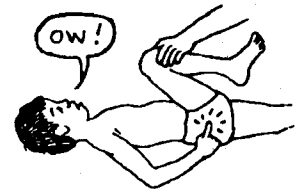
DIAGNOSIS: If a child has signs of one of these problems, try to get an **X-ray** to find out the cause.

SIGNS:

- Child begins to **limp:** body dips toward affected side.
- Often he does not complain of pain.
- Or he may feel some **pain** in the knee or thigh (or less often, hip)-although the problem is at the hip.

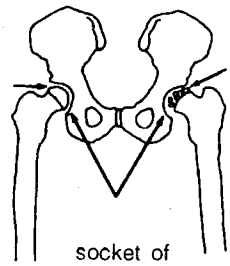


- Motion for bending, or opening of hip may become somewhat limited, or painful if he tries to bend it more.



- In time the thigh becomes thinner and weakness develops in the muscles that lift the leg sideways.

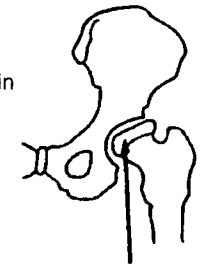




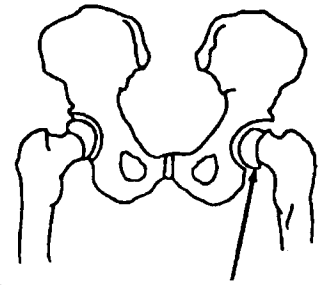
normal 'growth center' (cap on head of thigh bone)

pieces of damaged growth center in **Legg-Perthes disease**

socket of hip bone



flattened, deformed growth center after healing



slipped growth center

Destruction of the growth center is usually not related to other diseases. In some cases, however, destruction of the growth center from loss of blood supply is caused by tuberculosis of the hip, sickle cell anemia, cretinism, or use of corticosteroid medicines. A careful medical study is advisable.

Treatment and progress of Legg-Perthes disease

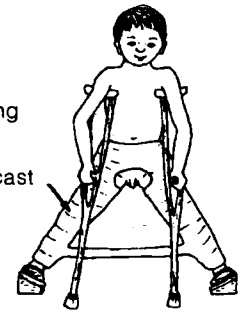
When the growth center has lost its blood supply, the bone dies and begins to break into pieces. At the same time, the body begins to make new bone. In 2 to 3 years a new growth center is completely formed, and the child walks more or less normally again, usually without pain. However, the new growth center is usually flatter than before and does not fit into the hip socket as well. As a result, after several more years, the hip joint begins to wear out and ***progressive,*** destructive, painful arthritis may begin.

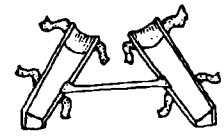
Many ways to treat Legg-Perthes have been tried. Most methods try to keep the leg in a position that makes the growth center form a round and normal shape again.

An old method was to prevent weight bearing and keep the hip bent in a sling. **THIS DOES NO GOOD.** We mention it only because in some countries children are still made to use slings and crutches for years.



A **newer method** was to cast or brace the **legs wide apart.**





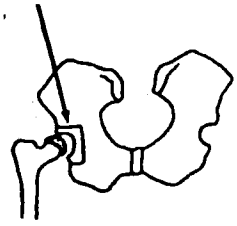
Full-leg braces



upper-leg braces only

Casts or braces were kept on the child until the new growth center formed completely–usually for **2 to 3 years!** This was very hard on both the child and family.

An even newer method was surgery. The surgeon cut loose a piece of bone containing the hip socket,



and turned it so the head of the thigh bone fit deeper into the socket. (The result was similar to widely separating the legs.)



Surgery was expensive and had more risks. But it was much quicker: only 6 weeks' bed rest with a cast.

Then the child could lead a more or less normal life, without slings or braces. But it still took 2 years for the new growth center to form, and during this time the pain and/or limp continued.

Recent studies show the **none of these methods–sling, casts, braces, or surgery–makes any real difference.** Treated or not, the pain and limp gradually go away-and are likely to come back as arthritis years later. Although many doctors still recommend one or another of these treatments, usually the **best advice to parents is to DO NOTHING.** (This is a hard decision for parents to accept, but will make life happier for both the child and family.) Let the child remain active, but do not make him run, jump, or walk far if it bothers him. **Moderate exercise is important. Swimming is excellent.**

Treatment and progress of slipped growth center

When the growth center slips, if possible it should be put back into place surgically, and pinned. When surgery is impossible, the child should avoid all strenuous exercise, running and jumping in the hope that the growth center will not slip farther until it becomes fused to the thigh bone (normally when the child is 16 to 18 years old). Without surgery, and especially if the slippage is severe, a progressive destructive arthritis is likely to result.

CHAPTER 19

Bone Infections

Osteomyelitis

Bone *infections* are mostly a medical problem. Therefore we do not describe all of the many types of bone infections or details of medical and surgical treatment.

Chronic (long-lasting) bone infections are fairly common in villages where persons go barefoot and where injuries and illnesses that can lead to bone infections are frequent. They can be caused by fungus, or by many different kinds of bacteria (including typhoid, tuberculosis, and staphylococcus). Often these infections last for years, causing bone destruction and severe disability.

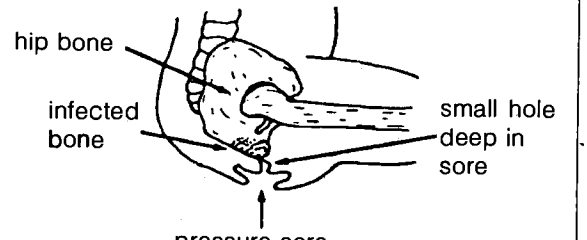
Bone infections are a very common complication of injuries, burns, and pressure sores in persons who have no feeling in their hands and feet. This includes persons with **spina bifida** (see p.201), **spinal cord injury** (p.230), and **leprosy** (p.263). Because the person does not feel pain, often she does not rest, clean, or protect the injured area. As a result, it becomes infected. Gradually the infection gets deeper until it reaches the bone.

THROUGH PROPER EARLY CARE OF SORES AND INJURIES,BONE INFECTIONS CAN USUALLY BE PREVENTED.

The loss of parts of the body sometimes seen in a person who has leprosy (Hansen's disease) is not caused by the leprosy germs. It is caused by other germs, which infect the bone because of injuries the person gets that are not cared for because they do not hurt.



WARNING: Deep pressure sores that do not heal, even after they are kept clean and no weight or pressure has been put on them for months, may have a bone infection. Bone infection is especially likely if the sore reaches the bone, or if a small hole at the bottom of the sore refuses to close and drains liquid or pus. **If you think there might be a bone infection, get medical help if possible and go through all the steps to treat it adequately.**



Signs of chronic bone infection

- The skin near a bone has small, deep sores that heal and then open again to drain pus., Gradually the affected area gets bigger and new holes open.
- There may or may not be pain
- The pus may or may not smell bad.
- Usually there is no fever-except sometimes at first or at times when the infection gets into the blood.
- Often the infection will get better with *antibiotics*, but keeps coming back.
- The affected bone may gradually become thicker as it is destroyed inside and forms a new bony covering.



Treatment

- Whenever possible get experienced medical help
- If treated early with the right antibiotics in the right (high) dosage, sometimes the infection will go away and not come back. If possible, a sample of the pus should be studied (cultured) by a medical laboratory to find out what kind of infection it is and what medicine is likely to work best. Usually the medicine should be taken for a long time (months).



The body nanaturally tries to repare the dead bones from the body Photo : Mathew Varghese

- If you cannot get the pus cultured, you might try treating the infections with dicloxicillin (a special penicillin). Use relatively high doses. For dosage and precautions, see ***"Where There Is No Doctor"*** or a medical text.
- Surgery may be needed to remove the dead, infected bone. When a bone becomes infected, portions of the bone become dead. With time, the body naturally tries to separate the dead bone from the body. However, some portions of the dead bone may still remain in the body and pus will continue to form. In such cases surgery is needed.
- Sometimes amputation is necessary (see p.263).
- Even with excellent treatment, after months or years without problems, new sores may open and again begin to drain from the infected bone.

Rehabilitation and aids

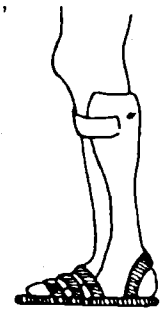
What kind of ***rehabilitation or orthopedic*** aids may be needed will depend on the amount of destruction that has occurred. Sometimes surgery cannot be obtained or the person may prefer to live with the problem rather than with an amputated limb.

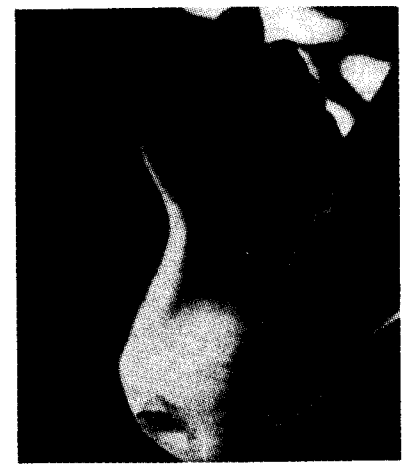
For prevention, rehabilitation, and aids, see Chapters 24, 26, and 59 on pressure sores, leprosy, and braces.

When there has been a lot of bone destruction, sometimes a brace can help make walking easier.

An infected bone becomes weak and brittle and can get fractured easily.

The brace can also help prevent these fractures.





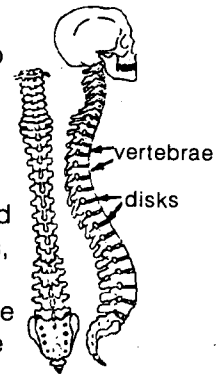
Large holes down to the bone in the foot of a woman with a bone infection (osteomyelitis). She has had this problem since childhood 30 years before.

WARNING: The pus coming from the infected bone may cause serious infections in other persons. Change bandages regularly; boil them before using them again, or burn them. Wash hands often. **Take great care with hygiene.**

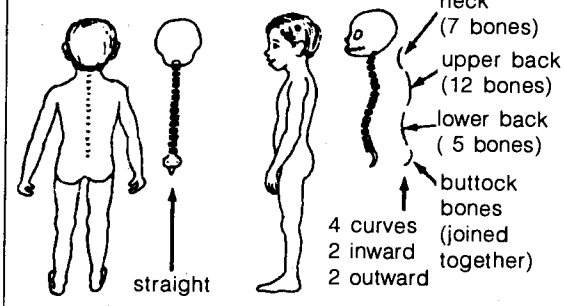
CHAPTER **20**

Spinal Curve and Other Back Deformities

The backbone, or ***'spine'***, is a chain of bones called 'vertebrae' that connect the head to the hipbone. Separating each of the vertebrae is a small cushion called a **'disk'**. The backbone holds the body and head upright. It also encloses, in its hollow center, the ***'spinal cord'*** or trunk line of nerves connecting the brain to all parts of the body (see p.37).



NORMAL SHAPE OF THE BACKBONE



Normally, the backbone (and back) is straight when seen from the back, and has 4 curves when seen from the side.

Sideways curve (scoliosis– S-shaped curve)



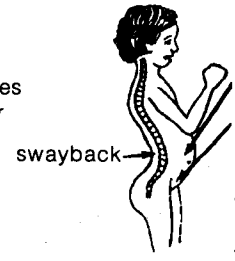
May result from unequal ***paralysis*** of back muscles or from a hip tilt due to one shorter leg. Sometimes the cause is not known.

Rounded back (kyphosis)



May result from weak back muscles or from poor posture (bent over position when standing or sitting)

Swayback (lordosis)



May result from weak stomach muscles, from hip ***contractures,*** or from the way a child walks to make up for a weak leg or hip.

Sharp bend *or* bump in spine (tuberculosis of the backbone)



Results from destruction of one or more vertebrae by tuberculous *infection* (see p.185)

Of these different problems, scoliosis or a sideways curve is the most common serious problem. Often, however, rounded and/or swayback are seen together with scoliosis.

NON-FIXED AND FIXED SPINAL CURVES

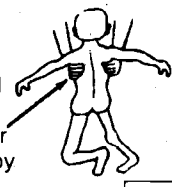
With a non-fixed or ***'functional'*** curve there is no deformity of the vertebrae. This usually happens when the body tries to stand straight even though the hips tilt or there is other unevenness not in the spine.



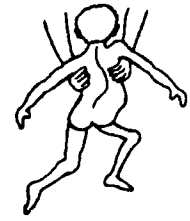
For example, a child with a shorter leg from polio will stand with his hips tilted. For him to stand straight, the spine has to curve.



A **non-fixed curve** can usually be straightened by putting blocks under the foot, or by holding the child up under the arms.



Fixed or 'structural' curves are deformities in the bones of the back themselves.



A fixed curve cannot be straightened by positioning or holding up the child.

Note: In some cases, with time a non-fixed curve may gradually become fixed.

CAUSES OF SPINAL CURVE (SCOLIOSIS)

Most **scoliosis** (about 80%) occurs in otherwise healthy children for no known reason. Sometimes it occurs in several members of the same family, so there may be a ***hereditary*** (familial) factor. Although about 1 of every 10 persons has some scoliosis (if looked for), only about 1 in 400 has enough of a curve to be a problem. **Curves of unknown cause are often first seen–and progress quickly–in children from 10-15 years old, during the period of rapid growth.**

Known causes of **fixed scoliosis** range from *infection* to tumor to rare disease. When possible, consult a doctor with experience in these problems.

Some children are born with fixed scoliosis, or develop it in early childhood, because of defects in the spine itself.

Sometimes one or more vertebrae are only partly formed and cause the spine to bend to one side.



Sometimes 2 or more vertebrae remain attached or 'fused' on one side. They can only grow on the unfused side, causing an increasing curve.

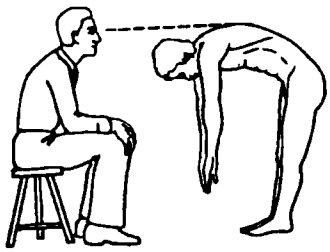


These problems can only be identified by X-rays.

Non-fixed scoliosis always results secondary to other problems, such as uneven paralysis of the back muscles, or a hip tilt (often due to a shorter leg). Spinal curve often develops in children with **polio, cerebral palsy, muscular dystrophy, spina bifida, spinal cord injury, arthritis,** and **dislocated hip.** Be sure to examine all children with these **disabilities** for spinal curve. With time, non-fixed curves may gradually become fixed.

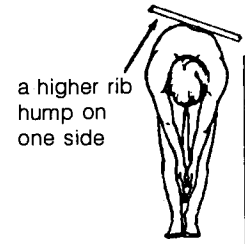
Examining for spinal curve

This is discussed in the chapter on physical examination (Chapter 4).

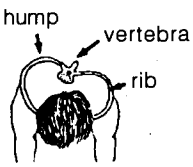




Look along the line of the back with the child bent over.



a higher rib hump on one side

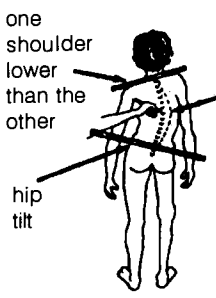


The rib hump is formed because where the spine is curved, the vertebrae also are twisted to one side.

POSSIBLE SIGNS OF EARLY SCOLISIS

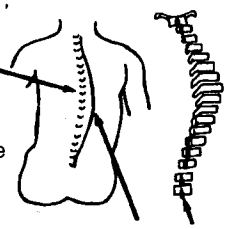
1. One shoulder higher than other.
2. One shoulder blade sticks out more.
3. One hip is higher or sticks out more than the other.
4. One arm hangs closer to body than the other.
5. Swayback.
6. Rounded shoulders or 'hump back'.
7. A larger crease at one side of waist than other.
8. Child stands sagging or leaning to one side.
9. Rib hump (when child leans forward).
10. A hump near the waist (when leaning forward).
11. A brother, sister, parent, or close relative with scoliosis.

CHECK FOR:



To see the curve better, mark the tip of each vertebra.

The actual spinal curve is greater than the curve you have marked.



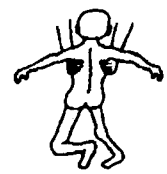
actual curve (as seen in X-rays)

overhead view of vertebra



When you examine for scoliosis, also check to see if the curve

can be straightened (non-fixed)



or cannot be straightened (fixed)

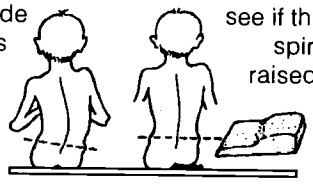


What to do

This will depend on:

- how severe the curve is.
- if it is getting worse–and if so, how quickly.
- whether the curve is fixed.
- the age of the child.

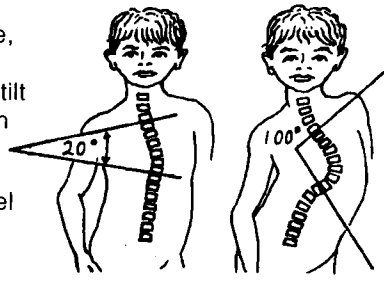
In a child who does not stand, check spinal curve while he is sitting. If one side of his buttock is weaker and smaller, it may cause a hip tilt.



Put a book or board under the weaker buttock, and see if this straightens his spine. If so, a cushion raised on one side may help him sit straighter.

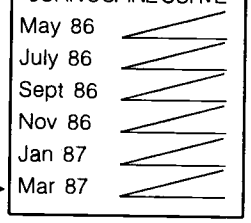
How severe the curve is and whether it is getting worse can be best measured by X-rays.

1. For each curve, pick the 2 vertebrae that tilt most in relation to each other.
2. Draw lines level with the top of each vertebra.



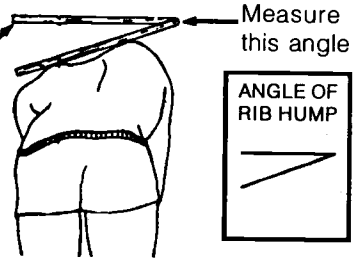
3. Measure and record the **angle of the spinal curve.**
4. Regularly record the curve and notice any changes.

JOHN'S SPINE CURVE



Because X-rays are expensive and often hard to get, you can get some idea of whether the curve is getting worse by measuring the **angle of the rib hump**.

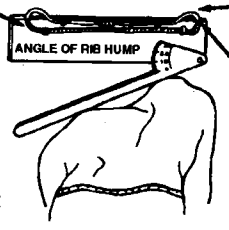
Be sure the top piece is completely level. You can use a carpenter's level or a homemade one (see box).



Have the child stand or sit as straight as possible, while he bends forward.

A homemade level for measuring rib hump angle

Fill the tube with colored water so that the water reaches the top edge of the board at both ends when level.



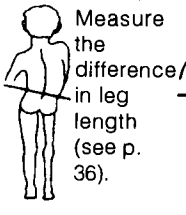
piece of thin plastic tube (old I.V. tube)

When measuring the rib hump, level the top by making sure the water is at the top edge of the board at both ends.

If the rib hump angle stays about the same month after month, the curve is probably not getting worse. Keep checking it every few months. If the rib hump angle increases steadily, the curve is getting worse. X-rays should be taken and a decision made about what to do.

Non-fixed curves that are not getting worse should usually be treated only by doing something about the underlying problem.

For example, if the child's spinal curve is not fixed and comes from a hip tilt due to unequal leg length:



Measure the difference in leg length (see p. 36).

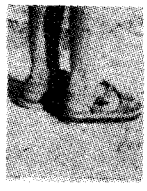
Level the hips by standing on books or boards.



Put a lift on shoe or sandal (see p.669)



This child was developing a spinal curve due to hip tilt and short leg.



Village rehabilitation workers put a lift on his sandal.



This corrected his spinal curve and lop-sided posture.

Body jackets or bracing for a non-fixed curve usually do not help to correct the curve or even to prevent its getting worse. However, for a child with a curve so severe that it makes sitting or walking difficult, a body jacket or corset may help.

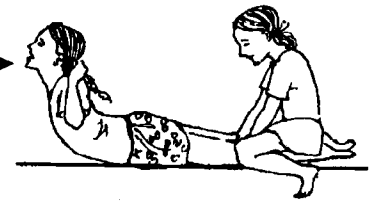


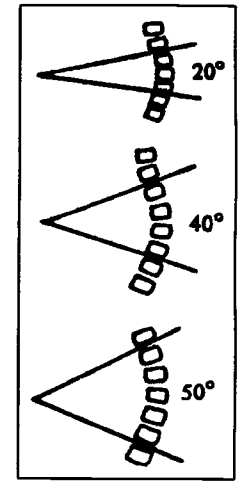


Instructions for making body jackets are on p.660

Spinal curves under 20° (fixed or non-fixed) usually need no special care–other than to be watched, and measured every few months to see if they are getting worse.

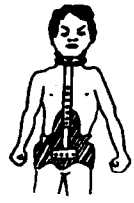
Some experts say that exercises to strengthen the back muscles, like this, help correct and slow down the curving of the spine. Other experts say it does not do much good. (We do not know).





Spinal curves over 20°, if they are fixed and getting worse, may get worse less quickly with a brace.

A brace like this is often used. It works because it is so uncomfortable that the child must stretch his body as straight as possible to reduce the discomfort.



A plastic 'Boston brace' like this is more comfortable, can be completely hidden under the clothes, and probably does as much good.



SURGERY

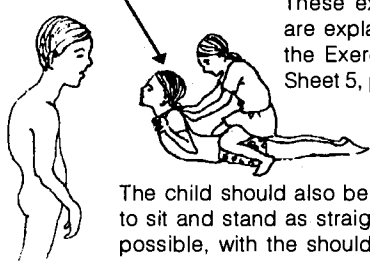
For spinal curves over 50° which are quickly getting worse, surgery may be needed. Surgery 'fuses' (joins together) the most affected vertebrae. Usually it only partly straightens the spine. Except for severe curves, surgery should be avoided in children under 12 years old because the fused part of the spine will not grow any more.

If the curve of the spine is less than 40° by the time the child stops growing, usually it will not progress further. If the curve is over 50°, it is likely to keep getting worse even after the child stops growing, and surgery is often recommended.

However, 'spinal fusion' surgery is very costly and requires an ***orthopedic*** surgeon specially trained in this operation. It can also be very hard on the child and family. When surgery cannot be obtained, a body jacket or brace should perhaps be used to help slow down the curve's progress. When a curve becomes too severe, there is no longer enough room in the chest for the lungs and heart to work well, and the child may get pneumonia and die.

EXERCISES FOR ROUNDED BACK AND SWAYBACK

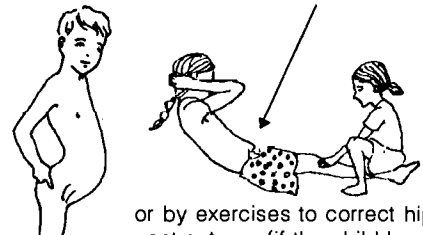
children with rounded back may benefit from exercises to help straighten it, like this



These exercises are explained in the Exercise Sheet 5, p.475.

The child should also be encouraged to sit and stand as straight as possible, with the shoulders back.

Children with swayback may benefit from exercises to strengthen the stomach muscles, like this,



or by exercises to correct hip contractures (if the child has them). See Exercise Sheet 3, p.473).

CHAPTER 21

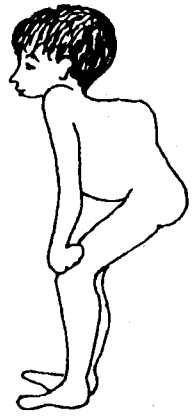
Tuberculosis of the Backbone

Pott's Disease

Tuberculosis (TB) of the backbone is not common, but is still seen in poor communities, especially in children. It is the most common form of tuberculosis of the bone.

It is important to recognize and treat it early, before damage to the backbone causes ***cord*** damage and ***paralysis.***

If a child begins to develop a sharp bend no matter how small in the middle line of the backbone, (with shortening and broadening of the chest in late stages), it is probably tuberculosis of the spine. You can almost be sure it is, if someone in the family has TB of the lungs or lymph nodes in the neck.

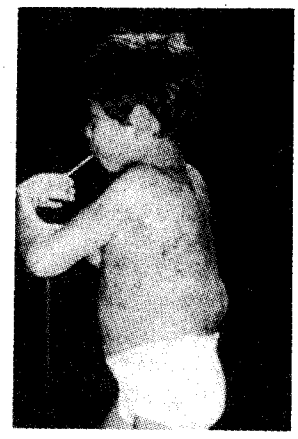


As the spine collapses forward, the child may have to hold himself up using his arms to reduce pain on movements.

Seek medical help quickly. Skin test, X-rays (of the chest and spine), and microscope examination of pus from abscesses (pockets of pus) may help in the diagnosis. If the X-ray shows typical bone destruction, the child should be treated for tuberculosis even if no TB germs are found.

SIGNS

- It begins little by little–often without pain at first.
- A bump develops in the backbone. This is because the front part of one or more vertebrae is destroyed and collapses.





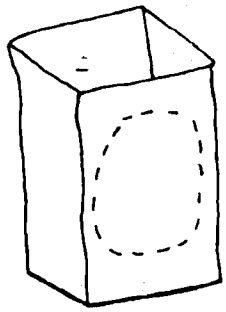
- The child has trouble bending over to pick things up.
- An abscess full of pus may form near the lump in the spine. It may gravitate (move) to lower level on the body and may occasionally burst discharging pus.
- As the condition gets worse, back pain may begin.
- Signs of ***spinal cord*** compression may develop: pain, numbness, weakness or paralysis in feet and legs, and loss of urine and bowel control. (like "Spinal Cord Injury," p. 203.)
- TB skin test is usually positive. (However, the skin test is of use only if the child has not been *vaccinated* against TB.)
- Often someone in the home has TB.
- Only a few children with TB of the spine may exhibit TB of the lungs.

Treatment

- Use 2 to 3 **TB medicines** for at least a year, as for TB of the lungs. (See ***Where There Is No Doctor, p. 258.)***
- A **back brace** may help keep the damaged spine straighter. It can be made of plaster, or of plastic using techniques similar to those used for making plastic leg braces (see p. 678).

  Or make a very simple back brace from a metal tin or drum where no doctor is available :

1. Cut an oval piece from a heavy tin.



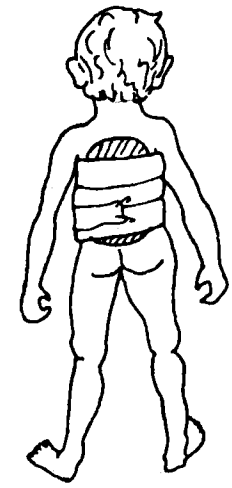
2. Hammer the tin to fit the child's back. Without forcing, try to put the back in the straightest position possible.



3. Pad the tin and wrap it with a soft cloth.



4. With an elastic bandage, bind the plate firmly to the child's back.



CAUTION: Make sure the bandage does not hurt the child, damage his skin, or make it difficult for him to breathe.

The child in the photo on the previous page was effectively braced by a traditional bonesetter in this way. Improvised braces can be effectively used. Brace is needed when the child is sitting or walking and to encourage the child to sleep on his stomach on a firm bed.

- In severe or advanced cases, **surgery** may be needed to help stabilize the bones of the spine, and to treat paralysis.

CAUTION: Because of the risk of paralysis, an orthopedic surgeon should be consulted if possible.

Hopes for the future



Such a severe deformity in developing countries is generally caused by tuberculosis of the backbone. An early diagnosis and correct treatment is important to prevent it.

With early, complete treatment the damaged bones will usually heal and the child may live normally, although often somewhat hunched over.

If cord/ nerve damage and paralysis have begun, an orthopedic surgeon must be contacted. Sometimes surgery (or even bracing during treatment) can bring some improvement. When even after surgery the paralysis has not recovered, ***rehabilitation*** will be the same as for spinal cord injury (see Chapters 23, 24, and 25).

PREVENTION consists of early diagnosis and treatment of tuberculosis, and in the fight against overcrowding, poor nutrition and poverty. Vaccination against TB may also help.

NOTES

CHAPTER 22

Spina Bifida

WHAT IS SPINA BIFIDA

Spina Bifida is a defect in the early development of the baby when it is in the womb. It happens when some of the back bones (vertebrae) do not close over the large ***central nerve***, (the spinal cord). As a result, there remains a soft unprotected area of the spinal cord which bulges out in the centre of the back. This bulged out area (sac) may contain the covering (meningeal membrane) of the spinal cord with fluid (cerebro-spinal fluid) and sometimes either nerve fibres or even a part of the spinal cord. It may be covered by very thin skin or normal skin.

The cause of spina bifida is not known. One out of every 750-1000 live born babies have spina bifida. In India, it is more common in the northern parts.

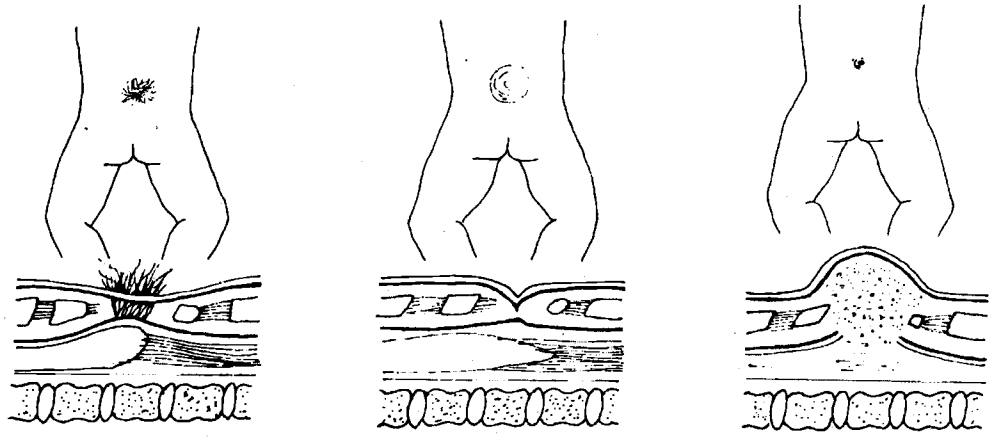
All spina bifida are not alike. All of them do not contain nerve fibres or the spinal cord in the sac. In some , the sac may be very small, but the spinal cord lies exposed on the surface. The problems at the time of birth and later are dependent on the kind of spina bifida and where it is located.

TYPES OF SPINA BIFIDA

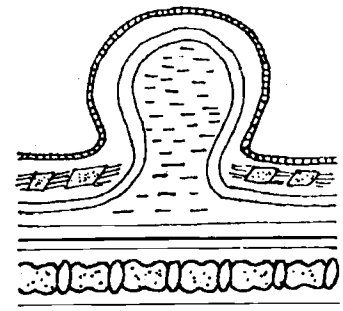
Spina bifida can be divided into two broad groups : a) Spina Bifida Occulta, b) Spina Bifida Cystica.

1. Spina Bifida Occulta : In this condition there is ***no bulge*** (sac) on the surface but there is non-closure of the vertebrae around the spinal cord. In a large number of these children the condition is indicated by the presence of skin lesions at the site of the spina bifida occulta. The child may have tufts of hair, a dark pigmented skin or a deep pit in the skin at the site.

   These babies usually have no problem at birth but later, problems which come with a defect in the spinal cord; loss of control over passing of urine & stool, pressure sores, or paralysis of the lower limbs, can occur.

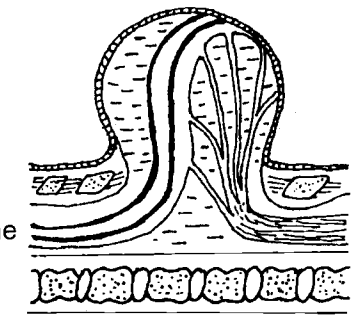


2. Spina Bifida Cystica : In this condition there is a bulge (sac) on the surface of the back because of the non-closure of the vertebrae. The problems that these children will face, at birth or later, will depend on the contents and nature of the sac. There are 3 types of Spina Bifida Cystica.



(i) Meningocele : The sac on the back is covered by normal skin. It contains only fluid and covering of the spinal cord. It does not contain any nerve fibres.

These babies will have a swelling in the back but no associated problems either at birth or later.



(ii) Meningomyelocele : This is a common and difficult condition. The bulge is in the centre of the back. It contains fluid, the coverings of the spinal cord and also either the nerve fibres or part of spinal cord. The sac may be covered by very thin skin, or, there may be no skin covering at all.

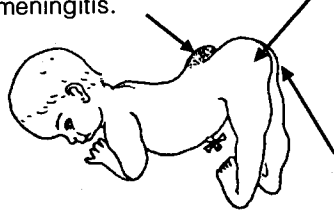
These babies are born with problems such as paralysis of the legs and loss of control in the passing of urine & stool. The **seriousness of the defect** depends on the location of the spina bifida on the back i.e. whether it is situated in the upper or lower part of the back.(see p.193 to 194)

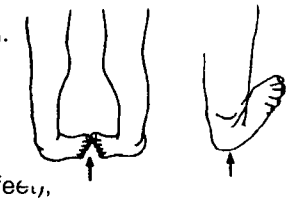
(iii) Myelocele : In this condition the ***spinal cord lies exposed*** on the surface, like a red ribbon like structure in the centre of the back. It is not covered by its coverings or by the skin. The fluid leaks continuously. The baby is usually born with paralysis of the legs and a loss of control in passing urine and stool.

Problems Associated With Spina Bifida At Birth

Most of these problems occur usually when the child has either Meningomyelocele or myelocele.

- *High risk.* Without early surgery to cover the bag of nerves, it almost always gets *infected* and the child dies of meningitis.





- **Muscle weakness and loss of feeling.** The legs or feet may be **paralyzed** and have little or no feeling.
- **Hips.** One or both hips may be *dislocated.*
- **The feet** may turn down and in (club feet), or up and out.
- If the defect is relatively high up the back (L1 or above, see next page), there may be *muscle spasms (spasticity)* in the legs and feet (see p. 204).
- **Poor urine and bowel control.** The child may not feel when he pees or has a stool. When he gets older he may not develop control, and will pee or shit without knowing it.

- **Big head.** 'Hydrocephalus' which means 'water on the brain', develops in 4 out of 5 children with spina bifida. The liquid that forms inside the head cannot drain normally into the spinal cord, so it collects and puts pressure on the brain and skull bones. Although the child's head may look normal at birth, little by little it becomes swollen with liquid, like this.



- very big head
- big veins
- The eyes may turn downward because of pressure in the head. This 'setting sun sign' means **danger** of blindness and severe brain damage.

- **Brain damage.** Without early surgery to lower the pressure of the liquid in the head (and sometimes even if the surgery is done), some children become blind, mentally retarded, have fits (epileptic seizures, see p.283), or develop cerebral palsy (see Chapter 9)

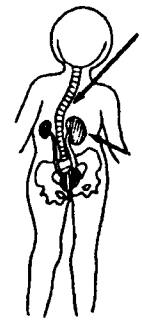
WHAT TO LOOK FOR WHEN A BABY IS BORN WITH SPINA BIFIDA

- First of all examine the baby to see if there is any other birth defect which may be serious. For example – a heart defect. If the nails, lips and tongue of a newborn child are blue, he may have a damaged heart. Take the child to a health worker immediately.
- Try to make out the type of spina bifida and where exactly it is located on the back.
- What is the size of the bulge and what is the condition of the skin covering it ? Is it normal, thin or very thin ? If some liquid is already leaking from the sac, or if the skin is very thin, take the child to a health worker or qualified doctor immediately. A very thin covering has more chances of breaking.
- Try to see if there is any movement or sensation in the legs.
- Does the child urinate at one go or is there dribbling of urine.
- Check to see if the child has a large head. The normal size of the head is 33-35 cm at birth.
- Are there any problems in the feet, joints or in the back bone.

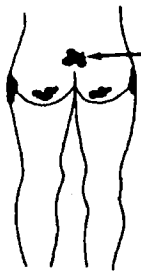
WHAT ARE THE PROBLEMS WHEN THE CHILD IS OLDER

Spina bifida may be associated with following problems when the child grows older:

- **Urinary Infections**:Because of poor control on the passing of urine, the bladder is never completely emptied out. The urine which remains in the bladder can get infected, later causing kidney damage. Urinary tract infection is one of the most common causes of death in children with spina bifida.
- **Curve of the Spine** : The spine may be curved at birth and this may become more marked later. It may also be the result of a dislocation at the hip joint or paralysis which is more marked in one leg.



- **Curve of the spine** (See Chapter 20.)
- **Urinary infections and kidney damage** (See p.247.)



- **Pressure sores** may form over the bones, because the child cannot feel. (See Chapter 24.)



- **Pressure Sores:** If the child cannot feel, pressure sores may form over the bony areas, due to pressure. These sores do not heal and gradually increase in size , getting infected, and even affecting the bone if not treated properly. (See chapter 19).
- **Posture:** Due to muscle weakness or paralysis of the legs, the child may not be able to sit or stand without support.
- **Foot injuries:** Children who can walk but have no feeling in their feet may easily develop sores or injuries. If neglected, these can lead to severe infections of the flesh, bone infection, and deformities or loss of the feet (see p. 263).
- **Contractures**: Incorrect postures may result in contractures.
- **Social problems**: Because of a lack of urine and bowel control, sometimes children with spina bifida get socially isolated. However, the community can be helped to understand the child's problem, and look for ways to integrate him.

WHAT IS THE FUTURE FOR A CHILD WITH SPINA BIFIDA

The future of a baby who is born with spina bifida will depend on the following factors :

- The type of the spina bifida and exactly where it is located on the back.
- The severity of the damage.
- General medical care and special training provided to the child.
- Support provided to the child by the family and the community.



If the spina bifida is located in the upper part of the back, usually the spinal cord is more damaged. This leads to a paralysis of legs and a loss of bladder and bowel control. The head is also enlarged in a large number of these children and there may be brain damage. An operation will usually not help. About 25 to 30% of these children usually die within the first year of life even if they are given the best treatment.

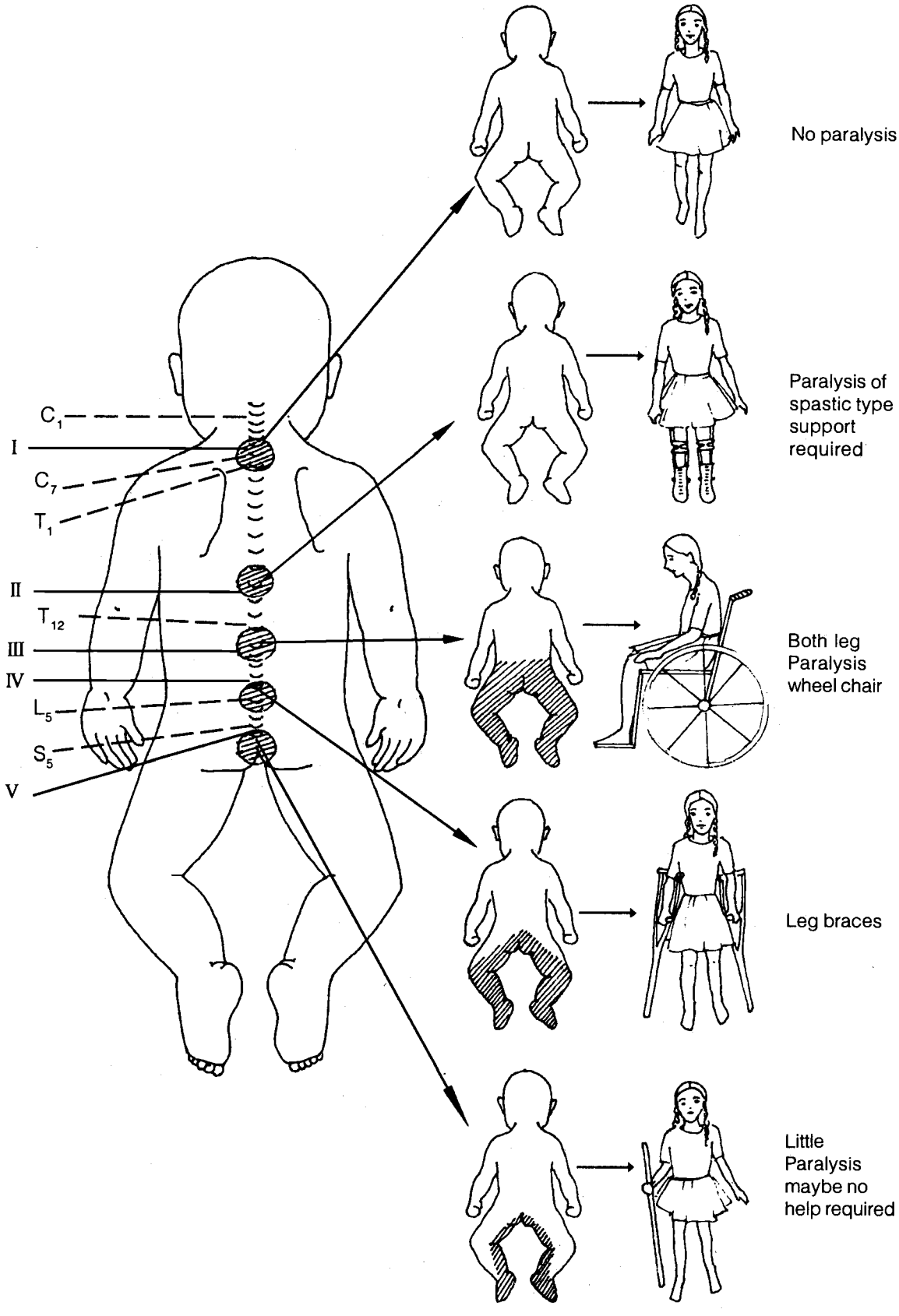
If the spina bifida is situated in the lower part of the back, usually there is less paralysis in the legs. These children have a good chance of leading a near normal life provided surgery is performed at the right time, and if they have the support of their family. They can attend school and learn to be independent later in life.

Often these children are late in learning the basic skills for self care (getting dressed, eating, going to the bathroom etc.). This is partly because of the ***disability***. But it is also because their parents often overprotect them and do everything for them. **It is important for parents to help these children to do more for themselves.**

WILL MY CHILD WALK

This is a common worry of most parents. Whether the child walks or not depends on factors such as :

- The nature of deformities in the muscles, bones and the joints of the legs.
- The location of spina bifida on the back: children with spina bifida can be broadly divided into 5 groups occording to the location of the bulge on the back.


C1
I
C7
T1
II
T12
III
IV
L5
S5
V
No paralysis
Paralysis of spastic type support required
Both leg Paralysis wheel chair
Leg braces
Little Paralysis maybe no help required

- **Location of Spina Bifida:** Children with spina bifida can be broadly divided into 5 groups according to the location of bulge on the back -

LEVEL OF DEFECT	PROBABLE AMOUNT OF DISABILITY
Group-I This is a rare occurrence. Found in only 1-2% of children with Spina Bifida.	Usually no paralysis of the legs. Can walk.
Group-II Found in about 25% of the children.	Some of these children may have paralysis of one or both legs. The paralysis is of the spastic type. These children usually walk with some support.
Group-III Found in about 25% of the children.	Both legs are usually paralyzed. The child has no control over when he urinates or passes stool. Will need a wheel chair. Surgery rarely helps. 1 out of 4 children die in the first year of life.
Group-IV Most common. Found in 45% of the children.	About half of these children will walk. The child may require long braces for walking. There is usually no control of passing urine or stool.
Group-V Found in 2 to 4% of the children.	Very little paralysis. Child will walk without support.

CARING FOR THE CHILD WITH SPINA BIFIDA

When there is a bulge on the spine of a newborn new baby, his chances of living are much better if he has an operation within a few weeks. The surgery covers the defect with muscle and skin.

This avoids the risk of injury and infection (Meningitis).

SURGERY

The babies who will benefit most by surgery should be identified at birth or immediately after birth. Operations are successful if the child :

- does not have paralysis in both the legs
- does not have a large head (hydrocephalus)
- has urine and bowel control
- does not have any severe life threatening birth defect
- does not have severe curvature of the backbone.

BEFORE SURGERY



AFTER SURGERY



The surgery is simple and can be done in any hospital where paediatric surgery or neurological facilities are available.

The ***timing*** of the operation is also very important. The operation should be done immediately after birth if :

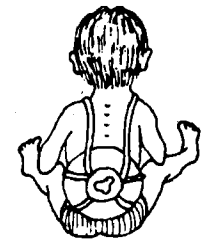
- The bulge is covered by very thin skin which is likely to burst leading to infection.
- The nerve fibres or the spinal cord are exposed.
- If the sac has burst and the fluid is leaking.

However, if the sac is covered by normal skin the operation can be done at any time.

In babies who cannot be operated, the bulge must be protected. In the early years these children are encouraged to be on their stomachs. Later, a ring or soft bag can be designed to avoid pressure on the bulge and also protect it.

You can make a ring or "donut" of soft cloth or foam rubber and you can tie it so that it surrounds the bag. Do not let the ring or clothing, touch the bag.





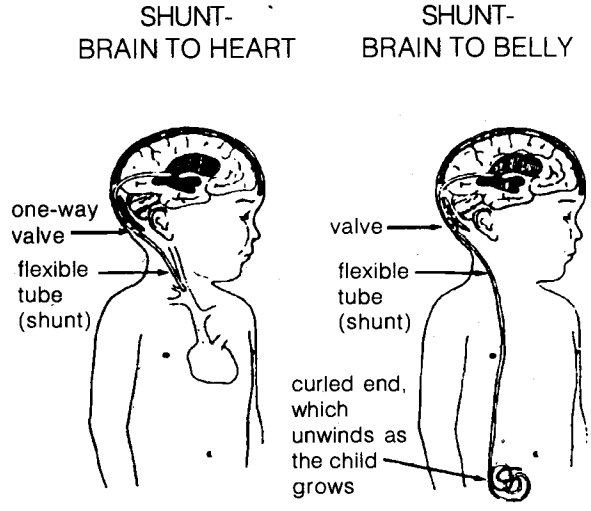
Hydrocephalus (Large Head)

At birth, the distance around the head is measured by a simple measuring tape used by tailors. The normal measurement of the head at birth is 33-35 cm and this increases gradually. (See chart on p.43). If the size of the head increases rapidly and is more than what it should be, or if you notice that the head is swelling a lot,the child probably has hydrocephalus.

.A surgical operation called a 'shunt' may need to be done before the pressure of the liquid in the brain causes much damage. Shunt tubes are made of transparent silicone rubber with valves which allow the fluid to pass only in one direction. One end of the tube is put in a cavity in the brain filled with fluid. The other is left in the stomach. This tube drains the extra fluid from the brain into the stomach from where it gets easily absorbed.

After the shunt operation, the child requires regular follow-up. Complications such as blockage, or infection of the shunt can occur and require immediate treatment.

The shunt operation is done only for children whose head measurement increases rapidly. If the head is not very large and stops increasing the operation is not needed.



CAUTION: 'Shunts' do not always give good results. Even with surgery, 1 out of 5 children with hydrocephalus dies before age 7, and more than half become mentally retarded. Other are intelligent, however, and develop normally. Before deciding on the operation, get advice from 2 or 3 specialists.

Note : We realize that, for many families, the operations described here will not be possible. Except where free hospital services are available, they are costly.

Before deciding on surgery, there are several things to consider:

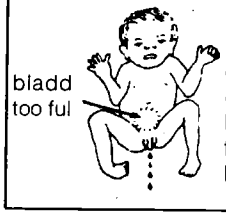
- What will the child's future be like, if he lives? Is he likely to suffer greatly, or might he have a chance to live a full and happy life, despite his limitations?
- If the family spends much money on operations, and then on daily care of the child, how will this affect the health and well-being of the other children in the family?

In short, before deciding whether to operate, it is important to consider carefully how this may affect the quality of life for both the child and the family.

BLADDER AND BOWEL MANAGEMENT

A child with spina bifida usually does not develop the same control of urinating (bladder control) and passing stool (bowel control) as other children do. The child may always dribble urine. Or, as she gets older, she may continue to empty her bladder or bowels without warning, perhaps without even knowing or feeling it. **Standard methods of toilet training will not work. Do not blame or scold her for her accidents.**

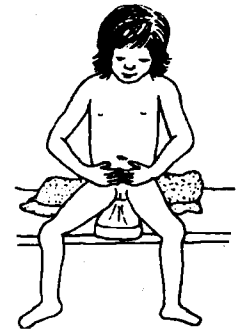
WARNING: In some children with spina bifida, the bladder does not empty completely. This is dangerous because if urine stays in the bladder for a long time, bacteria will grow in it and this can lead to infection of the bladder and kidneys. The child gets fever, looses weight and feels nauseous. In children with spina bifida, urinary infections are a frequent cause of death.



Urinary infections can lead to damaged kidneys and finally to kidney failure.



A mother can learn to feel how full the bladder is, and to tap on it gently to see if this makes the baby urinate. If not, she can regularly press gently on the bladder to push out the urine.



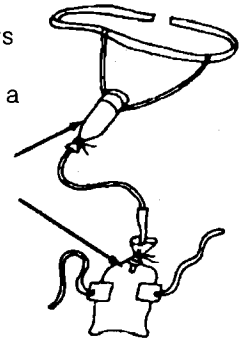
Later, some children can learn to empty their bladders by crying, rolling over, laughing, or sneezing. Others learn to do it by pressing on the stomach, like this, although this can also be risky (see p. 246)

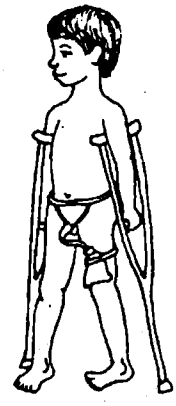
Some children may need to use a 'catheter' or rubber tube to get the urine out. By age 5 they can often learn to 'catheterize' themselves. (See p. 242)

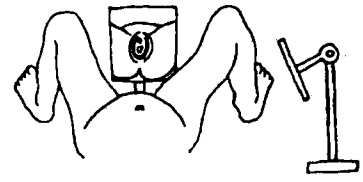


Girls often need to empty the bladder regularly with a catheter, and perhaps use diapers (nappies) to catch any urine that drips out in between.

As they grow older, boys are often able to use a 'condom' connected to a bag that collects the urine. (See p. 244)







For girls, a mirror helps in finding the urine hole.

IMPORTANT INFORMATION on **urinary and bowel problems** and **prevention and treatment of urinary infections** is in Chapter 25, p. 233 to 246. Be sure to study this chapter!

Sometimes none of these methods can be successfully used with a child. In such cases surgery is required. The urine is surgically diverted to the body surface for collection in a bag.

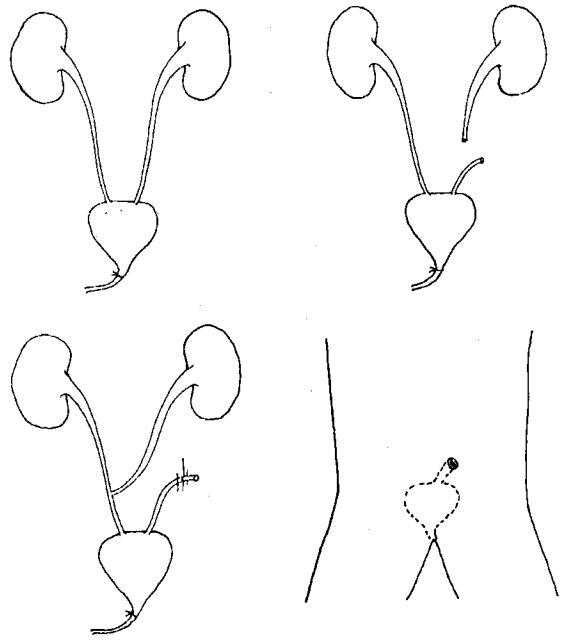
Two methods are commonly used :

1) A small part of the large intestine (ileum) is cut out. The two ureters (that carry the urine from the kidneys to the bladder) are attached to this part of the large intestine. One end of the intestine is brought out to the abdominal surface.

   The urine is collected here in a bag.

2) One of the ureters is cut and attached to the other ureter. The part of the ureter that remains attached to the bladder is diverted to an opening in the abdominal wall.

   The neck of the bladder is closed. Intermittant clean catheter drainage can be done through the opening of the ureter in the abdominal wall.



Most children with spina bifida can be helped to take care of both their bladder and bowel so that they stay relatively dry, clean, and healthy. Then they can go to school and do things outside the home with greater confidence. Therefore, **it is extremely important that rehabilitation workers and family members help the child work out a good bladder and bowel program.**

PREVENTION and correction of contractures

Some children with spina bifida tend to develop ***contractures*** either because of muscle imbalance (see p. 88) or, less often, because of ***spasticity*** (abnormal muscle tightness). Contractures most often develop in the feet, hips, and knees. **Range-of-motion** and stretching exercises, as discussed in Chapter 43, can help prevent and correct early contractures.

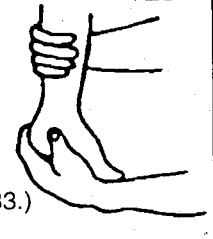
CAUTION: Only do stretching exercises where there is stiffness or limited range of motion. When joints are floppy, **do not stretch them more** where they already bend too much. For example :

YES

If the foot is stiff in this position,



do exercises to gradually bring the foot up. (See p. 383.)

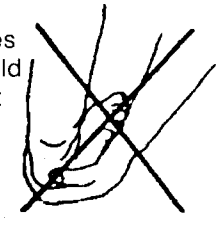


But if the foot is floppy or already bends up more than normal,

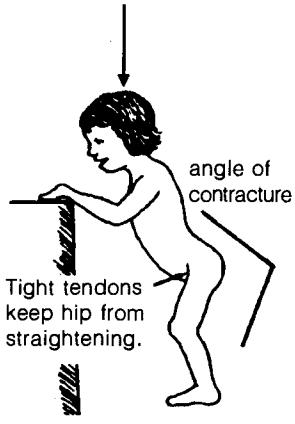


NO

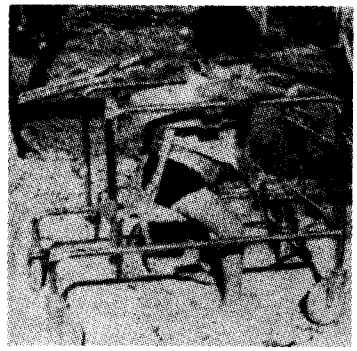
avoid exercises that would stretch it even more.



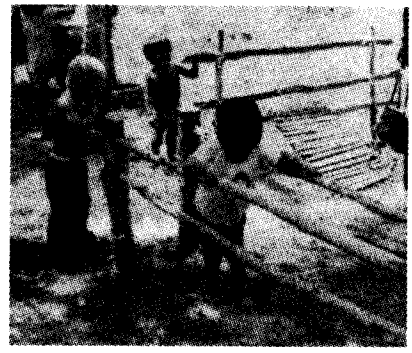
Because children with spina bifida have stronger muscles for bending than for straightening the hips, they tend to develop **hip contractures,** like this child. Stretching exercises (p. 473) and lying on the belly (p.96) may help.



Also, make sure walking aids help correct rather than increase the contractures.



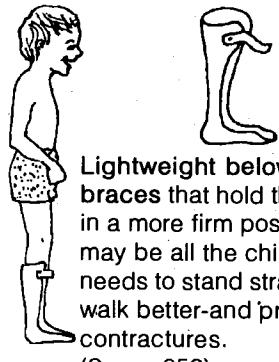
This expensive metal 'walker' lets this child with spina bifida 'walk' with hips bent. It can cause hip contractures and make walking without aids less possible.



When the child is changed to parallel bars adjusted to the right height, he walks more upright. This helps prevent contractures and increases the possibility of walking without aids.

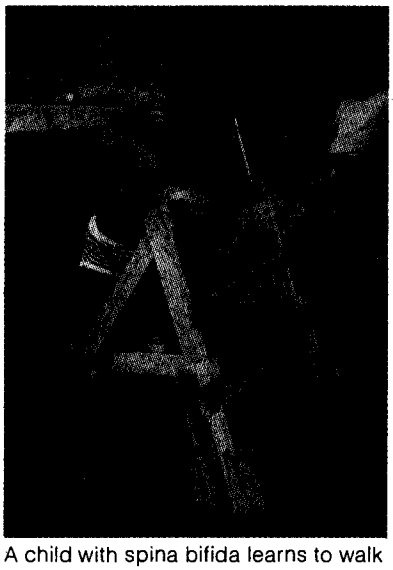
Sometimes a child stands with hips and knees bent, partly because his feet bend up too much. This can lead to hip and knee contractures.





Lightweight below-knee braces that hold the feet in a more firm position may be all the child needs to stand straighter, walk better-and prevent contractures.
(See p. 652)

Do not let the child get fat. Because the legs and feet of a child with spina bifida are weak, it is important that she does not get too heavy. Even for a child who does not walk, moving will be easier if she is not fat. Encourage her to eat nutritious foods, but to avoid a lot of sweets, fatty foods, and sweetened drinks.



A child with spina bifida learns to walk with the help of a homemade walker.

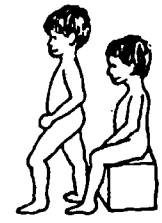
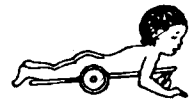


A one-year-old with spina bifida in a mini wheel chair made by disabled workers.

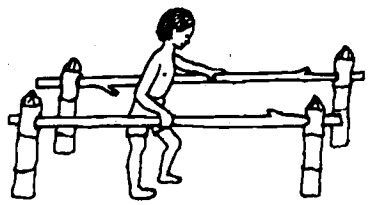
HELPING THE CHILD DEVELOP

Many children with spina bifida are paralyzed from the waist down. In spite of their disability, it is important for them to develop their bodies, their minds, and their social abilities as much as possible. Certain 'adaptive aids' can be used to help paralyzed children go through the same stages of development as able-bodied children, at close to the same age. (See the developmental chart on p. 360)

For the child to progress through the early stages of development, it is important that he can

SEE STRAIGHT AHEAD	SIT WITH HIS HANDS FREE	EXPLORE HIS SURROUNDINGS	STAND WITH HIS HANDS FREE	SIT, STAND, AND WALK
NORMAL 				
SPINA BIFIDA 				
If she cannot get herself into a position where she can see what is happening in front of her, lie her on a 'wedge' or fix a carton or box so she can sit leaning back in it.	You can make a seat from an old bucket or some other object, so that she can sit and play.	You can make a little cart that helps her to move. The cart can have a handle so that another person can push it.	Make a standing frame that holds her in a standing position. Holding up the weight of her body on her legs will strengthen her bones, so they will not break as easily.	She can use a brace that holds her up, so that she can walk with crutches. It helps if the brace has hip and knee hinges so that she can sit down (see p. 699).

When adapting aids for children with spina bifida, remember that each child is different. Some children manage to walk without braces, perhaps with the aid of parallel bars like these, and later crutches. Others will need above knee or below knee braces



(see Chapter 59). Other children will need wheelchairs.



This child with spina bifida learned to walk using elbow crutches adapted to form a walker. As his balance and control improved, the supports on the crutches were gradually removed until he could walk with the crutches alone.

Surgery and orthopedic corrections

To prevent or correct **foot contractures** in many children, it may be necessary to straighten the feet in the same way as for club feet (see p. 689). So that the contractures do not come back, the children will need to do exercises (see p. 128 and 471) and perhaps use simple plastic braces (p. 670), at least at night.

For curving of the spine, if severe, some children need surgery or a body brace. (See p. 184.)

For children with spina bifida who have **one hip dislocated,** corrective surgery is sometimes helpful. But surgery generally is not recommended for those children with **both hips dislocated.** Usually they will walk just as well if the hips are left dislocated- and with fewer complications and less suffering. (See "Hip Problems," p. 176.)

> *CAUTION:* Before any orthopedic surgery is performed on a child with spina bifida, carefully evaluate the possibility she has of walking and whether the surgery will really help her.

PREVENTION of pressure sores and injuries

As a child who has no feeling in parts of his body grows older and heavier, there is increasing danger that pressure sores (bed sores) will form over bony areas that support his weight (mostly his bottom of his feet). To prevent this:

- Have the child sleep and sit on a mattress or cushion that is soft (such as foam rubber), clean and **move or turn over often.**
- Examine the child's lower body daily for early signs of irritation or sores everyday. Check especially the hips, knees, and feet. Clean the child's body every day.
- When he is a little older, the child can learn to check his own body each day for sores.

DANGER: Whether the cause is spina bifida or leprosy, children who walk but have no feeling in their feet run a high risk of cuts, burns, sores, and serious infections on their feet. Teach them to **check their feet every day.**



Also, **be sure that sandals, shoes, and orthopedic braces fit well and do not cause blisters or irritation.** Shoes can have soft linings. Then examine the parts of the body that come in contact with aids every day.



This child with spina bifida cut her feet on broken glass. Because the cuts did not hurt, they were neglected and became severely infected. In time, the infection spread to the bones in both her feet and began to destroy them. As a result, her feet are very deformed and she may lose them completely.

> *IMPORTANT INFORMATION* on prevention and treatment of pressure sores is in Chapter 24, p. 229 to 237. **Be sure to read it.** Also see Chapter 26 on Leprosy, p. 264 to 267 for special footwear and ways to protect the feet.

PREVENTION OF SPINA BIFIDA

Parents of the child with spina bifida may want to know the chances of having another baby with the same problem. When compared to the general population, the chances of their having another baby with spina bifida are *higher*. If the mother gets pregnant again, she should go to a health post which has facilities for tests that will help her know if she is carrying another child with spina bifida.

Or she can go to the health worker who can refer her to one such facility.

Here, at 14 to 16 weeks of the pregnancy, the mother's blood (serum) or fluid which surrounds the baby in the womb (amniotic fluid) is tested for the presence of a particular protein, Alphabets protein. The presence of this protein indicates that the child can have spina bifida. The diagnosis can be further confirmed by ultrasonography of the uterus.

Once the parents know, they can take a decision on whether to terminate the pregnancy.

You will find other important information that relates to a child with spinal bifida in other chapters of this book, especially.

Chapter 23, "Spinal Cord Injury"

Chapter 24, "Pressure Sores"

Chapter 25, "Urine and Bowel Management"

Also refer to the chapters on contractures, club feet, exercises, developmental delay, braces, wheelchairs, and special seating.

CHAPTER 23

Spinal Cord Injury

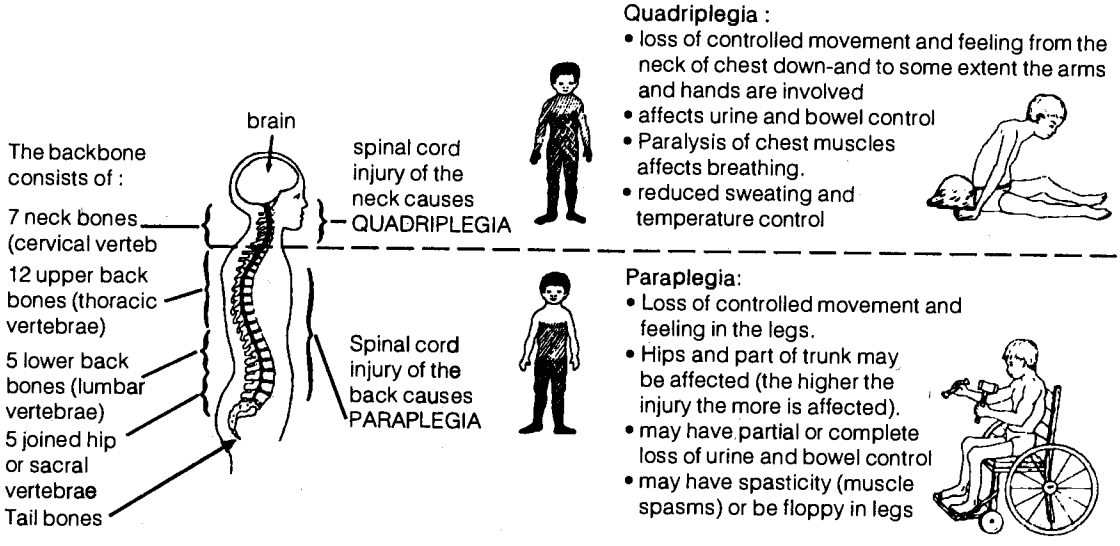
Spinal cord injury usually results from an accident that breaks or severely damages the central **nerve cord** in the neck or back:falls of old people in a soapy bathrooms, onunlit staircases,due to crush injuries during building construction, falls from trees or mules or into unprotected wells, automobile, mining and diving accidents, bullet wounds, and other injuries. Spinal cord injury is more common in young adults -and in general it is twice as common in men as in women.

The **spinal cord** is the line collection of ***nerves*** that comes out of the brain and runs down the backbone. (See p.37). From the cord, nerves go out to the whole body. Sensations of pain temperature, pressure and movement are controlled by messages that travel back and forth through the spinal cord. When the cord is damaged, sensations and movement in the body below the level of the injury are lost or reduced.

The incidence of spinal cord injury in children is low in India as compared to industrialised countries as the modes of injury are different.

Level of the injury

How much of the body is affected depends on the level of the injury along the backbone. The higher the point of injury is, the greater the area of the body that is affected.



Complete and incomplete injuries

When the spinal cord is damaged so completely that no nerve messages get through, the injury is said to be 'complete'. Feeling and controlled movement below the level of the injury are completely and permanently lost. If the injury is 'incomplete', or partial some feeling and movement may remain. Or feeling and controlled movement may return (partly or entirely) little by little during several months. In incomplete injuries, one side may have less feeling and movement than the other.

X-rays often do not show how complete a spinal cord injury is. Sometimes the backbone may be badly broken, yet the spinal cord damage may be minor. And sometimes (especially in children) the X ray may show no damage to the backbone, yet the spinal co rd injury may be severe or complete. Often, only time will tell how complete the injury is.

EARLY QUESTIONS THAT A SPINAL CORD INJURED CHILD AND FAMILY MAY ASK

"Will my child always remain paralyzed?"



It is very unusual that a child who is paralyzed by a broken neck is walking with a neck collar in 6 weeks.

This will depend on how much the spinal cord has been damaged. If paralysis below the level of the injury is not complete (for example, if the child has some feeling and control of movement in her feet) there is a better chance of some improvement.

Usually the biggest improvement occurs in the first months. As more time goes by without improvement, the less likely it is that any major improvement in feeling or movement will occur.

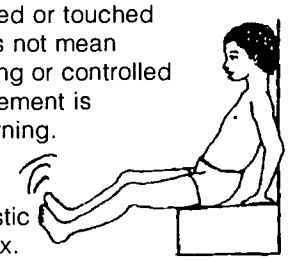
Surgery is done for stabilising the spinal column. Any neurological recovery after surgery must be considered as a bonus. However such a recovery is very rare.

After 2 to 3 months the paralysis that remains is almost certainly there to stay. As gently as you can, help both the child and parents accept this fact. It is important that they learn to live with the paralysis as best as they can, and not wait for it to get better or go from clinic to clinic in search of a cure.

It is best to be honest with the child and the family. Explain the facts of the situation as clearly, truthfully, and kindly as possible.

"My child's feet are beginning to move!"-spasticity

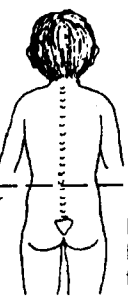
CAUTION: Sudden jumping or stiffening of the legs when moved or touched does not mean feeling or controlled movement is returning. This is a spastic reflex.



Immediately after a spinal cord injury the paralyzed parts are in 'spinal shock', and are loose or 'floppy'. They seem lifeless. Later (within a few days or weeks) the legs may begin to stiffen-especially when the hips or back are straightened. Also, when moved or touched, a leg may begin to 'jump'(a rapid series of jerks, called 'clonus').

This stiffening and jerking is an automatic reflex called 'spasticity'. It is not controlled by the child's mind, and often happens where spinal cord damage is complete. It is not a sign that the child has begun to feel where he is touched or is recovering control of movement. It is a sign of permanent damage of the cord.

Some children with spinal cord injury develop spasticity; others do not.



level between 1st and 2nd lumbar vertebrae.

If the spinal cord injury is above the level of the top edge of the hipbone(above the 2nd lumbar vertebra) spasticity is very likely.

SPASTIC

FLOPPY

If the injury is below this level, paralysis is usually floppy(no muscle spasms).

Severe spasticity often makes moving and control more difficult. However, the child may learn to use both the reflex jerks and spastic stiffness to help her do things. For example,



When the child wants to lift her foot, she hits her thigh, triggering the jerks that lift the leg.

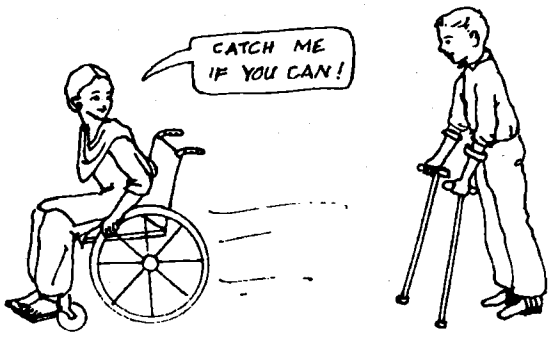


In lower back injuries, the spasticity or stiffness of the legs may actually help the child stand for *transfers*.

"Will my child be able to walk?"

This will depend mostly on how high or low in the back the injury is. The lower the injury, the better the chance of walking. A person with complete spinal cord injury in the neck has no chance of walking. She will need a wheelchair.

If the child's injury is in the lower back and if his arms are strong and he is not too fat, there is a chance he may learn to walk with crutches and braces. But he will probably still need a wheelchair or tricycle to go long distances.



Many spinal cord injured persons prefer a wheelchair to walking with braces and crutches.

It probably makes sense to give most paraplegic children a chance to try walking, for example, between parallel bars. However, do not make the child feel guilty if he prefers a wheelchair. Let the child decide what is the easiest way for him to move about.

Many children who do learn to walk find it so slow and tiring that they prefer using a wheelchair. Standing and walking even for a short period every day will help to prevent contractures, deformities, bone softening and other secondary complications that can make a child with a spinal cord injury more disabled than he needs to be.

For independent living, other skills are as important as walking, and the family and child should place equal importance on these: skills like dressing,bathing,getting into and out of bed, and toileting. Self-care in toileting is especially important-and is more difficult because of the child's lack of bladder and bowel control.



A child who is paraplegic learns to walk with a plywood parapodium made by village rehabilitations workers (PROJIMO)

"What are the hopes for my child's future?"

The chances of a paraplegic's leading a fairly normal life are good-provided that you:

1. avoid 3 big medical risks:
   - skin problems (pressure sores)
   - urinary infections
   - contractures (shortening of muscles, causing deformities)

   (*Contractures* are not a danger to life but can make moving about and doing things much more difficult.)
2. help the child to become more self-reliant:
   - home training and encouragement to master basic self-help skills such as moving about,dressing,and toileting
   - education:learning of skills that make keeping a household, helping other people, and earning a living more possible

It is more difficult for quadriplegic (all limbs paralyzed) persons to lead a normal life because they are more dependent on physical assistance. However, many paraplegics and a few quadriplegics can manage to lead full,rich lives, earn their own living,get married,and play an important role in the community with effort and organization, the same possiblities can exist in all countries.

"Can anything be done about loss of bladder and bowel control?"

Yes. Although normal control rarely returns completely,the spinal cord injured child often can learn to be independent in his toilet,and to stay clean and dry (except for occasional accidents). Often he will need a special urine collecting device,will learn to use a catheter, and will learn to bring down a bowel movement with a finger or suppository. Management of bladder and bowels are discussed in Chapter 25.

> VERY IMPORTANT INFORMATION ON URINE AND BOWEL CONTROL IS IN CHAPTER 25. BE SURE TO READ THIS CHAP TER!

"What about marriage,sex,and having children?"

Many spinal cord injured persons marry and have loving, sexual relationships. Women with spinal cord injruies can become pregnant and have normal babies. Men may or may not be able to get a hard penis or ejaculate (release sperm). Paraplegic and quadriplegic men whose injuries are incomplete are more likely to have children. Some couples where the husband cannot release sperm decide to adopt children.



Especially for young men, fear of the loss of sexual ability is often one of the most fearful and depressing aspects of spinal cord injury. Honest, open discussion about this, and the possibilities that do exist, with a more experienced spinal cord injured person may help greatly. There is a good discussion of this in **Spinal Cord Injury Home Care Manual** See reference, **p.770.**

HELPING THE CHILD AND FAMILY ADJUST

Spinal cord injury, especially in the child, brings many of the same problems as does spina bifida. Also many aspects of rehabilitation are similar. (We suggest you read Chapter 22 on spina bifida to get additional ideas for the **rehabilitation** of young children with spinal cord injuries.)

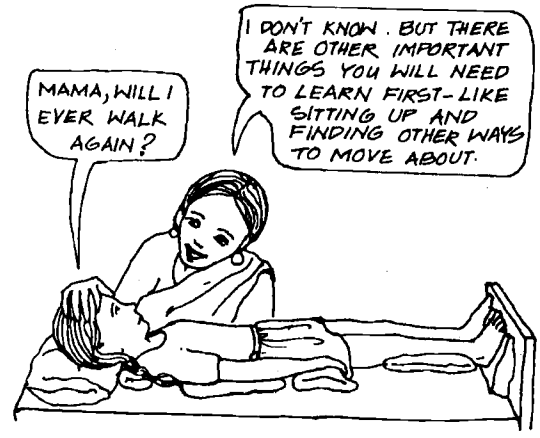
Perhaps the biggest difference from spina bifida is that spinal cord injury begins later. One day the child is physically active and able, the next he is suddenly paralyzed and (at first) unable to do much for himself. He has lost all feeling and control in part of his body; it is like a dead weight.

This is very hard for the child-and family-to accept. Both have an enormous fear and uncertainty about the future. The child may become deeply depressed, or angry and uncooperative. He may refuse even to sit in a wheelchair because this means accepting not being able to walk.

There are no easy answers to the child's fear and depression, but here are some suggestions families have found helpful.

- Recognize that **the child's fear, depression, and anger are natural responses** and that with love, understanding and encouragement, he will little by little overcome them.

- **Be honest** to the child about her/his ***disability***. Do not say, "We will find a cure for you," or,"Soon you will get well and be able to walk again." Very probably this is not true, and telling the child such things only makes it more difficult for the child to accept her disability and to begin shaping a new life. Also, as the promised 'cure' fails to happen, the child becomes more uncertain, distrustful, and afraid. In the end, it will be much easier for her if you gently tell the truth. Here is one example. →



- Provide opportunities to **keep the child's mind active: playing, working, exploring, learning** through stories, games, and studies. But at the same time **respect and be supportive of the child when he feels sad and frightened.** Let him cry, comfort him when he does, but do not tell him not to cry. It is a safety valve. Crying helps relieve fear and tension.

- **Start** the child with **exercises, activities, and relearning** to use her hands and body as soon as possible, ie. start exercises to strengthen the upper limbs even while the child is lying in bed awaiting the spinal fracture to heal. Start with what the child can do, and build on that.

- Try to have the child watch, talk with, and get to know other persons with spinal cord injury (or children with spina bifida), especially those who are living full and happy lives.

- Invite the child's friends to come visit her, play with her, and let her know that they are eager for the day she will be back in school.

- **Encourage the child to do as much for herself as possible.** Let her do anything she can do for herself-even if it takes longer.

Help in ways that let the child do more for herself

- As much as possible, avoid 'tranquilizers' or `sedatives' (medicines meant to put one to sleep) or other strong medicines. The child needs an alert mind and an ability to move actively all day.



Look for ways to help spinal cord injured persons learn skills and play a useful, helpful role. Here 2 young, spinal cord injured persons in PROJIMO examine a disabled child, and give recommendations to the family, using an early draft of the original version.

HOW TO PREVENT MORE SEVERE SPINAL CORD INJURY IN CASE OF ACCIDENT

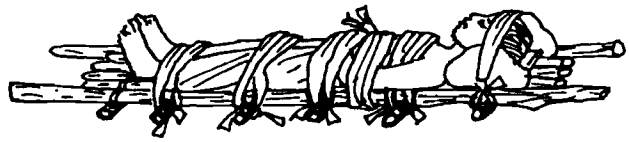
When a person has just had an accident that may have injured the spinal cord, great care must be taken to prevent further damage.

After an accident, there may be spinal cord injury if:

- the person is unconscious, or
- the person cannot move, cannot feel, or has numbness in his legs or hands.

If you think the spinal cord might be injured:

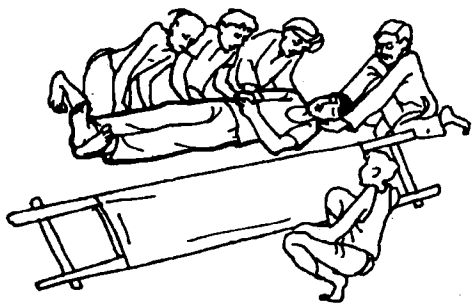
- Do not move the person until a health worker or a first aid worker with a large board or stretcher arrives. Especially **avoid bending the person's neck and back.**
- Lift the person without bending him, onto a board or stiff stretcher. (A stiff rack is better than a soft stretcher. Make one out of poles from trees or whatever is available). Make ties or strips of clothing or whatever you can.



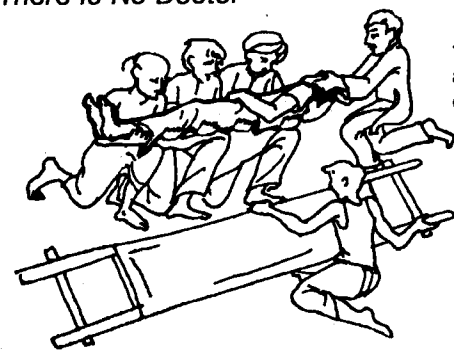
- If possible pad the board with clothing, cotton wool or soft grass or hay etc.
- Tie him down firmly and stabilize his head.
- Carry the person to a medical center or hospital. Try not to bounce or jiggle them.
- In case the person is unconscious or likely to vomit, carry him in the side lying position, with the spine aligned straight as shown in picture 2.

HOW TO LIFT A SEVERELY INJURED PERSON ONTO A STRETCHER

from: ***Where There Is No Doctor***

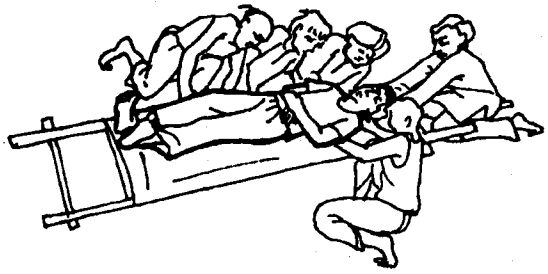


With great care, lift the injured person without bending him anywhere.

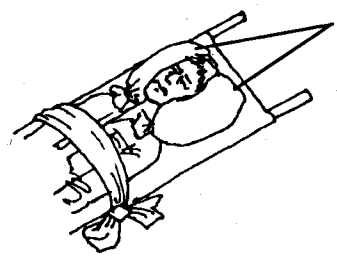


Make sure that the head and the neck do not bend.

Have another person put the stretcher in place.



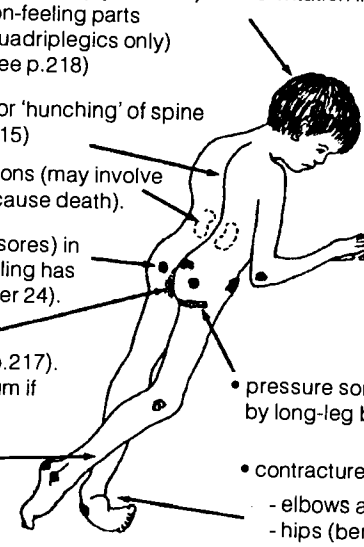
With the help of everyone, place the injured person carefully on the stretcher.



sandbags

If the neck is injured or broken, put bags of sand or tightly folded clothing on each side of the head to keep it from moving.

Common secondary problems in children with spinal cord injury



- Leg bones do not grow as fast, become thin and weak, and can break easily, especially if the child does not bear weight on them. (See p.222).
- sudden high blood pressure with pounding headache (dysreflexia) due to irritation in non-feeling parts (quadriplegics only) (See p.218)
- periods of depression, anger and difficulty accepting disability (See p.206)
- occasional Heterotopic ossification (new bone formation in the soft tissue) around hip/knee/elbow joints.
- increased risk of pneumonia in quadriplegics, due to weak breathing muscles (See p.213)
- Child suffers greatly in hot weather because body loses ability to control its temperature (See p.218).
- curving or 'hunching' of spine (See p.215)
- urinary infections (may involve kidneys and cause death).
- pressure sores (bed sores) in body areas where feeling has been lost (See Chapter 24).
- rash or sores between legs due to loss of urine and bowel control (See p.217). Prolapse (slipping out of place) of rectum if constipation persists.
- burns or other injury where body cannot feel (See p.216)
- pressure sores causes by long-leg brace.
- spasticity causes legs to straighten and pull together and feet to 'tiptoe' stiffly (See p.204)
- contractures-especially of
  - elbows and hands (in quadriplegics)
  - hips (bend up and pull together)
  - tiptoe and club foot deformities
  - especially in small children (See p.215).

To prevent or reduce the harmful effects of these problems, **special precautions need to be taken early and continued throughout life.**

EARLY CARE FOR THE SPINAL CORD INJURED PERSON

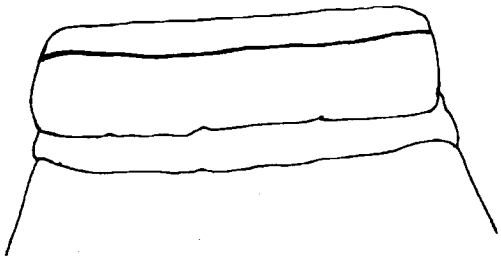
Early care following spinal cord injury is best done in a hospital, especially if the child is likely to get **good nursing care**. Family members should stay with the child in the hospital to make sure the child is kept clean and turned regularly, so that the bed sores and pneumonia are avoided. (Busy hospital staff with little experience treating spinal cord injuries sometimes let severe bed sores develop-which may threaten the child's life).

In case it is not possible to transport the child to the hospital, keep the child flat on a firm bed and ensure that the child is turned (log rolled ie. rolled from one side to the other keeping the spine straight. (See page 232) day and night for 6 to 12 weeks depending on the level of the injury. Injuries of the neck and the lumbar spine require 3 months of lying still. Injuries of the dorsal spine (where ribs are present) may need only 2 months of lying still. A soft pillow underneath the fractured spine will help restore the normal relationships of the bones and ligaments and can be used to turn patients as well. Every time the child is turned, check the skin for a pressure sore. Encourage the child to use both hands when lying in bed.

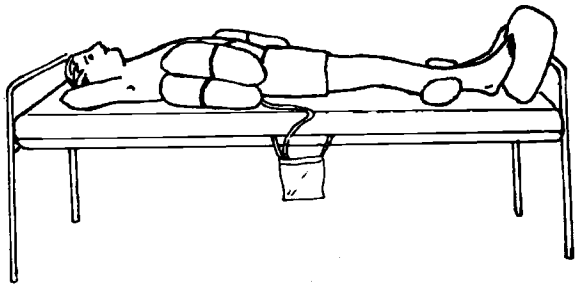
CAUTION: During the first 6 weeks, or until any breaks, in the bone have healed, **take great care when turning the child so that the angle of his back, neck, and head does not chage.** Use the same methods and precautions used in lifting a newly injured person into a stretcher (see p. 208). When the neck or back has healed, the child can start lying on his stomach, at first for 10 minutes and then longer if there are no problems.

The damage already done to the spinal cord cannot be corrected, either with surgery or medicine

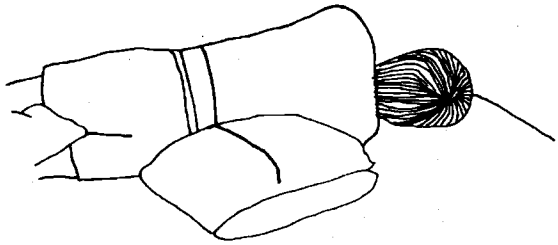
Madras Method of Log Rolling is a simple, effective and low budget method of management. It needs only one person for turning the patient and prevents complications. Any family member can do it. This method can also be used for patients with other chronic illnesses who are liable to get bed sores.



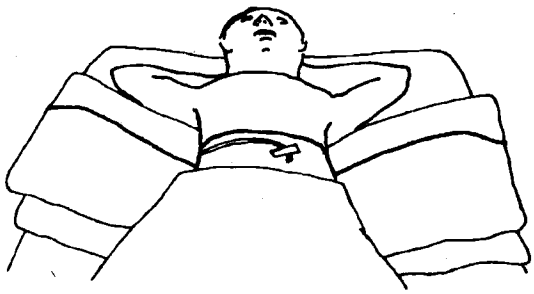
Two foam rubber or rubberised coir or ordinary flat pillows as wide as the bed are laid on the bed. A gentian violet mark is drawn over the middle of the upper pillow.



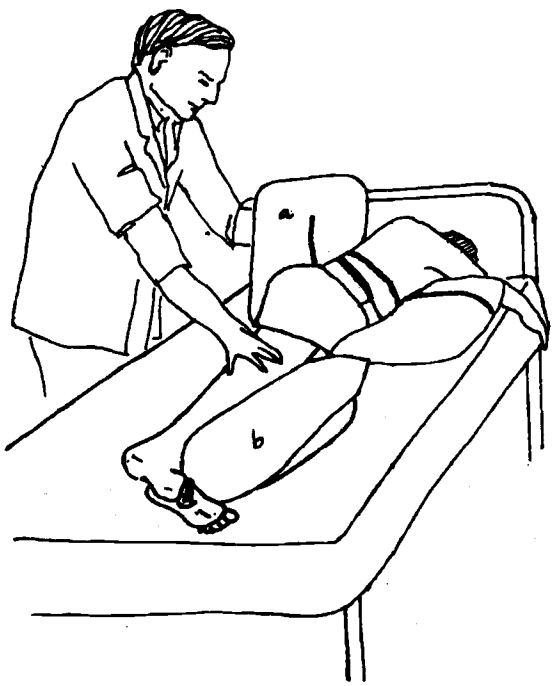
The side view showing the pillows correcting the deformity or disability. For support a foot board is placed and also ankle pads.



A mark is made on the patient at the level of the deformity.



The patient lies on the pillows with the marks on his body exactly on the mark made on the pillow.



A third pillow is placed between the legs. The upper pillow is used to log roll the patient from his back to his side, first to the left and then to his right side. The turning is done every two hours.

From: THE CHALLANGE AND THE RESPONSE Dr. T.K. Shanmugasundaram, Madras Paraplegia Project.

Healing of the spinal fracture

You will know the fracture has healed when the child feels no pain over the fractured area when it is pressed. This happens generally after 2to 3 months. It is ideal to get an X ray done to check for healing, but if it is not possible then the child can be turned to lie on one side and asked to gently bend his spine backwards and forwards. If there is no pain then it is safe to start the process of movement. If possible get the opinion of a doctor.

Movement

Once the fractured spine has healed, the child can be shifted on to a trolly on wheels and can move around. The spine is gradually loaded by gently tilting the child a few degrees every day on an inclined plane, always looking out for pain in the back and fainting spells (see page 216). After tilting the child a few degrees, that position is held for 30-45 minutes and this is repeated every day,gradually increasing the incline until the child is standing straight. Children with high spinal cord injuries are more likely to feel faint and therefore may need to have their legs bandaged and their abdomen supported with an abdominal binder to reduce fall of blood pressure due to standing posture. Once they can tolerate the vertical position for more than 30-45 minutes they are ready to start learning to walk.

REHABILITATION GOALS IN A CHILD WITH SPINAL CORD INJURY

1. Education of the child and the family in spinal cord function and spinal cord injury.
2. Training in appropriate movement.
3. Training in self care and activities of daily living.
4. Prevention of deformities and pressure sores.
5. Bladder and bowel training and prevention of complications.
6. Control of vasomotor dysfunction (postural hypotension and autonomic dysreflexia).
7. Maintenance of nutrition without letting the child become fat.
8. Control of pain
9. Sex education
10. Emotional and social adjustment
11. Introduction of appropriate recreation and sports
12. Return to home and school
13. (for parents) Information on financial and other assistance available from the government and other agencies.
14. Regular lifelong followup.

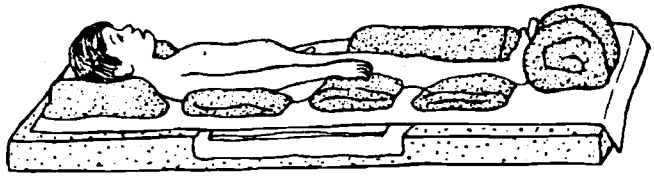
PREVENTING PRESSURE SORES (bed sores)

When feeling has been lost, pressure sores can easily form on the skin over bony areas-especially on the hips and buttock. The biggest risk of sores is in the first weeks after the injury. This is because the child, due to paralysis, must stay very still, and has not yet learned to move or turn over his body. Prevention of pressure sores is extremely important, and needs understanding and continuous care, both by the child and those caring for him.

BE SURE TO READ CHAPTER 24 ON PEVENTION AND TREATMENT OF PRESSURE SORES.

Summary: early prevention of pressure sores (For details, see Chapter 24).

- Lie on a firm bed covered with a soft mattress or thick,firm, foam, rubber pad.
- Place pillows and pads to keep pressure off bony areas.
- Change position (turn over, as a log rolling movement, from front to back and side to side) every 2 to 3 hours. To avoid pressure sores, lying on the belly is the best position).
- Keep skin and bedclothes clean and dry. In hot and dry weather do centripetal massage of all limbs and trunk three times a day using a clean wet towel.
- Eat good food rich in vitamins, iron and protein.
- Move the normal limbsand exercise a lot to promote good flow of the blood.
- Check skin daily for earliest signs of pressure sores-and keep all pressure off beginning sores until the skin is healthy again.
- Do not use talcum powder.
- Do not use hot water bag (for relief of retention of urine) counter irritant like balm, can be used.



Larger soft pillow under the fractured area for reduction of the fracture and for turning.

AVOIDING CONTRACTURES

In the first weeks following a spinal cord injury, when the child is in a lying position, joint contratures (muscles shortening) can easily develop, especially in the feet aand elbows. Pillows and pads should be placed to keep the feet supported, the elbows straight, and the hands in a good position. Gentle range-of-motion exercises of the feet, hands and arms should begin as early as possible, taking care not to move the back until the injury is healed. Further discussion on the prevention of contractures in the spinal cord injured is on p.215).

PHYSICAL THERAPY FOLLOWING SPINAL CORD INJURY

ASSISTED BREATHING AND COUGHING

Persons with spinal cord injury in the neck or upper back often have part of their breathing muscles paralyzed. Slowly the remaining muscles become stronger and breathing improves. But breathing often stays weak. The person may not be able to cough well and can more easily get pneumonia.

To help the person cough, place hands as shown below. Ask him to cough, and as he does, push firmly inward on the chest. Be careful not to move the backbone.

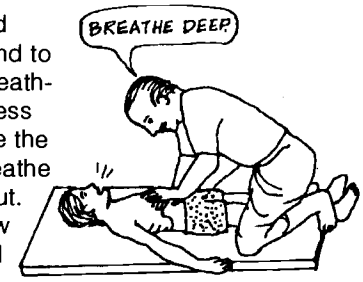
TWO-PERSON ASSISTED COUGH

Do this several times a day when the person has a cold, and more often if the person develops more trouble breathing or seems to have a lot of mucus in his lungs or throat.

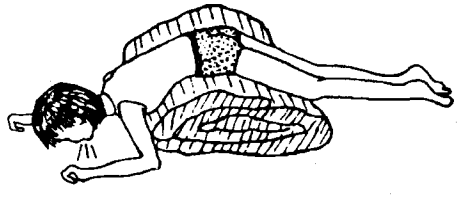


ONE-PERSON ASSISTED COUGH

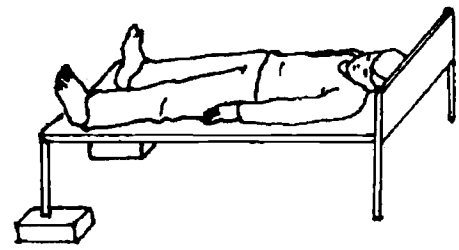
To help the child breathe deep and to stimulate the breathing muscles, press lightly here while the child tries to breathe deeply in and out. Do this, for a few minutes, several times a day.



If the person has a lot of mucus in her lungs, it also helps to lie her down, like this. and pat her back briskly. This helps loosen the mucus so that it can be coughed out. Be sure she drinks a lot of water to help loosen the mucus.



Gravity can also be used to drain the mucus and pus from the lungs by raising the foot end of the cot or bed on bricks or blocks.



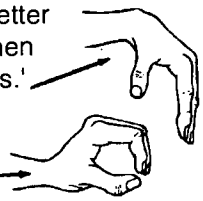
MOVEMENT AND EXERCISE

Do range-of-motion exercises for about 10 minutes for each arm and leg. In the first weeks do this twice a day. Later, once a day may be enough. If any signs of contracture develop, spend more time and effort on those parts of the body. From the start, exercises should be both **passive** (someone else moves the child's body parts.) and whenever possible, **active** (the child does it himself).

Range-of-motion exercises should begin with great care the day after the spine is injured (see chapter 43). The exercises will help to impove the flow of blood to prevent contractures, and to build the strength of the muscles that still work. Range-of-motion exercises should be **continued throughout life,** when possible, as a part of day-to-day activity. However too forceful exercises may result in the disruption of muscles and tissue and may produce abnormal bone formation (myositis ossificans) around the hip or knee joint.

CAUTIONS :

- Until any breaks or tears in the spine have healed (6 weeks or more) exercise must be very gentle and limited, with smooth motions and no jerking.
  - ◆ Especially at first, take great care that exercises do not move the position of the back and neck. Start with feet, ankles, hands, wrists and elbows.
  - ◆ If exercises trigger severe muscle spasms or jerking, do not do them until the break in the back bone is healed.
- Do not use force in trying to get the full range of motion, as joints can easily be damaged.
- For quadriplegics often it is better to stretch 'the fingers only when the wrist is bent down like this.'

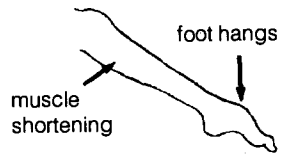


but not when it is bent back like this.

This way enough contracture is left to be useful for taking hold of things. Although the fingers lack movement by muscles, they close around an object when the wrist is bent back.

If possible, get instructions from an experienced *physical therapist.*

- Try to keep the full range of motion of all parts of the body. But **work most with those joints that are likely to develop contractures,** especially:
  - ◆ paralyzed parts that tend to hang in one position, such as the feet.



Prevent this through exercises(see p 471) and by supporting feet(p 215).

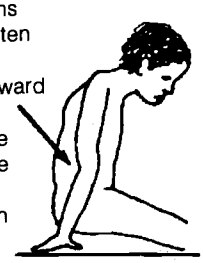
  - ◆ or, joints that are kept straight or bent by spasticity or by muscle imbalance (see p.88). For example:

In quadriplegia the muscles that straighten the elbow are usually paralyzed.

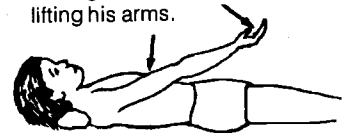


While the muscles that bend the elbow stay fairly strong. These muscles keep the elbow bent, and in time they shorten so that the arm can no longer straighten fully.

It is important that the arms can straighten until they bend backward a little- which is the only way he can lift himself with his arms.



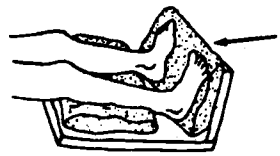
For this reason, straight arm positioning and early range-of-motion exercises for the elbow are essential. While he is still kept lying down, teach him to straighten his elbows by turning his hands up and then lifting his arms.



MAINTAINING HEALTHY POSITIONS

The position that the body is in during the day and night is also important to prevent contractures.

Contractures that cause 'tiptoeing' of the feet can develop easily, especially when there is spasticity. **Keep the feet in a supported position** as much of the time as possible:



when lying down, and when sitting



Teach the child to make sure his feet are in a **good position.**

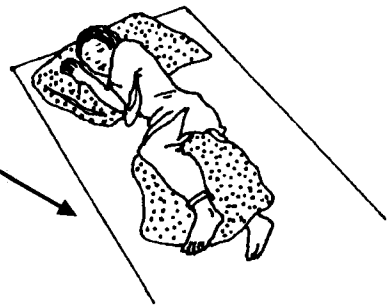
Even for the child who may never walk, maintaining the feet in a flat position makes moving from chair to bed, toilet or bath easier.

CAUTION: A support like this works well with floppy feet, but may trigger spasticity or jerking of the feet. Position them slowly.

Another common problem for children with spasticity is that the knees pull together and in time contractures prevent the legs from separating. To prevent this, when the child lies on her side she should learn to

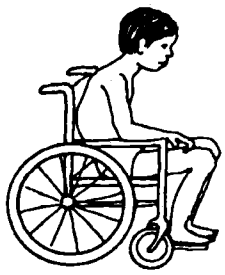


Place a pillow between the legs, and to keep it there most of the time.



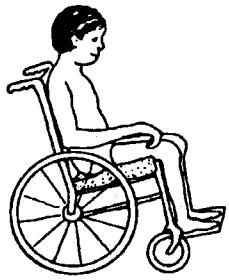
A common problem with wheelchair users is that they slump forward. In time this can deform the spine.

In a wheelchair with a straight-up back a person with spinal cord injury slumps like this in order to balance.



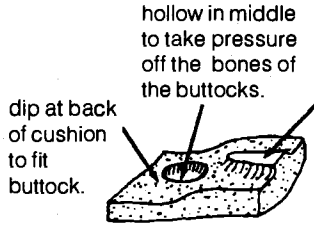
LESS APPROPRIATE

A chair can be designed (or adapted) so that it tilts back. This provides balance for a better position.



MORE APPROPRIATE

A special cushion also helps keep the buttocks from sliding forward (and helps prevent pressure sores).



If possible, make cushion out of 'micropore' foam rubber (foam with very tiny bubbles). Rubber-coated coconut fiber (coir foam) also works well.

For more suggestions for wheelchair adaptations, see Chapters 65 and 66. For more ideas on cushions, see p.233 and 234.

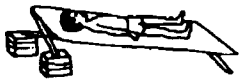
EARLY PHYSICAL RE-EDUCATION

The goal for a spinal cord injured person is to become as independent as possible in doing what he or she wants and needs to do. But even before the skills of daily living are relearned, the person needs to **learn to protect the body where functions that used to be automatic have been lost.** The protective functions that may be lost or changed include:

1. Adjustment of blood pressure to changes in body position.
2. Feeling (including pain) that protects from injuries (such as bed sores and burns).
3. Sense of body position and ability to keep balance.
4. Muscle strength and coordination.
5. Control of body temperature-especially keeping cool in hot weather.

1. **A sudden drop of blood pressure in the brain when the person rises** from lying to sitting, or sitting to standing, can cause dizziness or fainting. This is a common problem in spinal cord injury because the blood pressure adjustment mechanism is partly lost. Little by little the body can be helped to re-adapt, but precautions are needed (These same precautions are for anyone who has been kept lying down a long time).

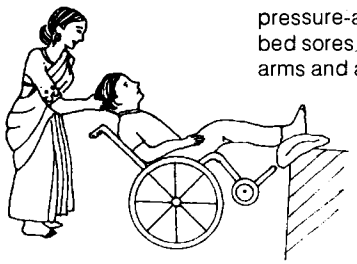
Before beginning to sit, raise the head of the bed-a little more and a little longer each day.



Start like this for 15 minutes.

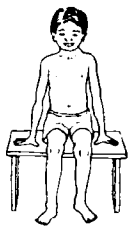


in a week or 2 build up to this for 3 hours.



If the person begins to get dizzy or faint when sitting, tilt him back and lift his feet.

Body lifting exercises help (pressing down with arms to lift buttocks) the body relearn to adjust blood pressure-and also prevent bed sores and strengthen arms and assist in toileting.



Before beginning to stand, make a standing board, and strap the child to it. Start at a low angle, and stand the board up more-and longer-each day.

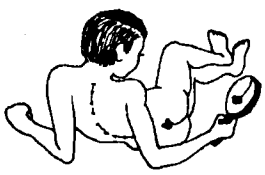


2. **The loss of feeling** in parts of the body can lead to **pressure sores and other injuries,** such as burns and cuts. This is because the body no longer feels pain and does not warn the child to change position or move away from danger.

It is important that the child learns to protect himself by changing positions often and avoiding injuries. This includes:



- learning to roll over
- turning at least every 4 hours when lying or sleeping
- lifting from sitting every 15 minutes (see p. 232)



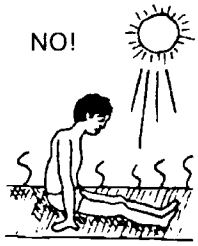
- examining the whole body every day for signs of injuries or sores.



- washing daily.

- learning to protect himself from burns and other injuries. For example,

NO!



DO NOT sit on or touch hot objects (or roads)

NO!



DO NOT sit, lie or sleep near an open fire.

Keeping clean is very important for persons with reduced feeling, especially if they lack bladder and bowel control. Take care to bathe daily. **Wash and dry the genitals, the buttocks, and between the legs as soon as possible each time they get wet or dirty.**

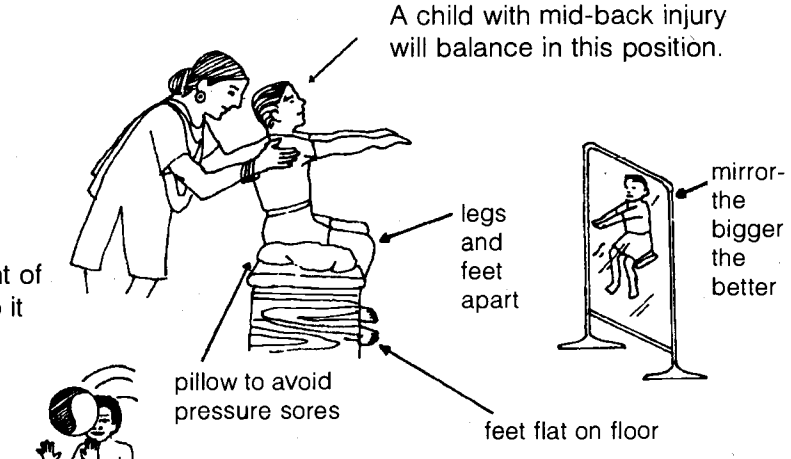
If redness, diaper rash, or sores develop, **wash more often** and **keep the sore area dry.** Keep the legs spread open and exposed to the air. When they must be covered, use soft absorbent cotton cloth. Putting a little vinegar in the rinse water after bathing the child, and after washing diapers and underclothes, helps prevent skin rash and **infection.** as it gives a sense of dryness - the powder should not be allowed to accumulate - but be cleaned away.

For treatment of specific skin infections (fungus, yeast,bacteria) consult a health worker or a medical book (like ***Where There Is No Doctor***, see Chapter 15).

3. **Loss of ability to sense what position the body is in** affects a person's sense of balance. So does loss of muscle control. The child needs to develop new ways to sense the position of his body and keep his balance. Start with the child sitting on a bench, if possible, in front of a mirror.

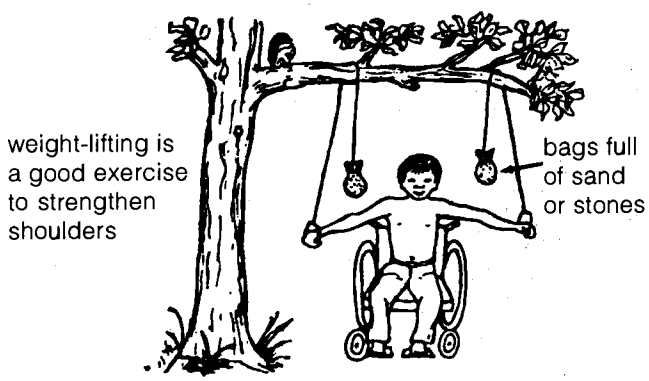
Help the child progress through these stages:

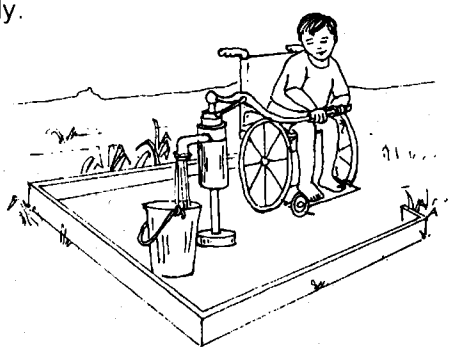
- both hands on bench
- both hands on knees
- lift one arm sideways, forward, and back.
- After doing this in front of a mirror, have him do it without the mirror.
- As the child gains better balance, start doing different movements with first one and then both arms, such as lifting weights or playing ball.



Note: Some children may have so much difficulty with balance that they may have to start in a wheelchair or a chair with high back and arm supports.

4. **Muscle re-education** All muscles that still work need to be as strong as possible to make up for those that are paralyzed. Most important are muscles around the shoulders, arms and stomach. Re-educate the normal rhythm of limb movement, bend one limb and straighten the other alternately.

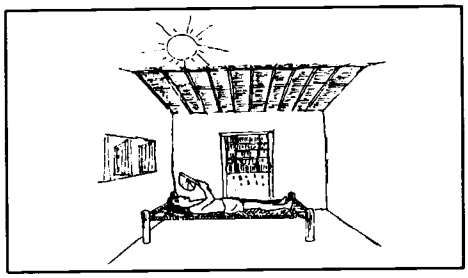




Look for ways to make the exercises useful and fun

5. **Temperature control** Normally, when a person feels hot, he sweats and the blood vessels beneath the skin swell or expand. This automatic cooling system is partly lost in persons with high spinal cord injury. In hot weather, they may get high fever or can even die of heat stroke. In hot weather exercises or work can be done early in the morning or late in the afternoon when it is cooler. In cold weather the body can become as cold as the weather itself.

For this reason they must learn (and be allowed) to rest quietly in the shade, in the coolest place possible during the hottest part of the day.

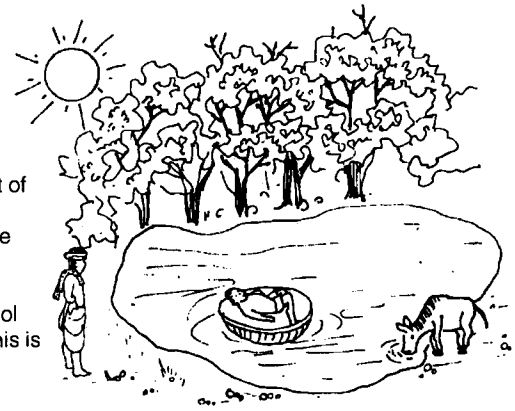


A Khus screen, or a thatch roof kept damp helps cool the air. Repeated cold sponging during the hottest parts of the day helps to keep the body temperature cool.



For hot weather, a wet towel for rubbing the body works very well for cooling the body. Repeated cold sponging helps in keeping the body temperature cool.

Children with spinal cord injury can learn to paddle around very well in old tire tubes. They love it, and it is excellent arm and shoulder exercise. **However, it is very important that someone watches them.**



If he can spend part of the hottest hours of the day in a shaded, shallow pool or pond, this is ideal.

TAKE CARE also to **protect against cold.** Body temperature can also drop too low in very cold conditions.

In cold weather to warm the body a Sigri in the far corner of the room may be kept. But ensure that the fire is far away from the patient.

6. **Deep vein thrombosis and Heterotopic new bone formation** are rare complications in children, but may be present in the older heavier child.

Deep vein thrombosis is clotting of the veins of the leg or pelvis. This results in the swelling of the leg. If the child has sensation in the legs, then there is increased pain in the limb. Even children who have no feeling in the legs may complain of increased burning sensation in the limb. If the clot is in the pelvis, both legs may get swollen. There are many causes for swelling of the feet, **so if possible, get the opinion of a doctor. If this is not possible,** and if the child does not have high fever or many pressure sores, start the child on 1/4 to 1/2 tablet of Asprin, once a day. (This small dose of Asprin is not enough to treat fever or joint pains, but is enough to decrease the chances of the clot growing).

Heterotopic ossification (new bone formation in the soft tissue) is another complication which is not very common in children, but when present can make the disability of a spinal cord injured child much worse.

Symptoms and signs usually present 2-6 months after injury: the child may have swelling and low grade fever and restricted joint movement. The swelling is often slightly warm and can be confused with infection. The joints involved most often are hips and knees. Elbows and shoulders are rarely affected. This complication, if discovered, also needs medical checkup and medicines by a doctor. If this is not available, allow the joint to rest as far as possible, in the functional position. Twice a day, **gently** move the joint through as much range as it will allow. **Do not force** the joint or it will get worse. Once the warmth and swelling begin to decrease, gradually increase the activities involving the joint.

7. **Curvature of the spine** About 2/3 of the children below 10 years of age who injure their spines develop curvature of their spines. These are often progressive and can initially make sitting and walking difficult and later also affect the breathing of the child. It is difficult to treat, but Chapter 20 (page 181) tells you how to treat spinal curves. The precaution to be taken is special care in preventing pressure sores under the spinal jacket by careful moulding of the jacket and ensuring that pressures are distributed over as large a surface as possible.

   The best way is to prevent this complication by ensuring that **every child with paraplegia is taught how to walk with braces and crutches.** Walking till the age of 17-18 years will minimise the chances of spinal curvatures developing. For qudriplegic (tetraplegic) children it is very important for them to stand in a frame for some time every day.(they can do part of their studies in the standing position).

8. **Chronic pain** is not a very common problem in children— but it is common in adults who have spinal cord injuries. When this does arise, it is important to examine the child carefully to look for pressure sores, chronic constipation, fissures in the rectum (anal canal), urinary complications, infected ingrowing toenails, fractures etc. as these can often be the *'cause'* of the pain. Removing the source can often reduce the pain. Tablets do not usually help. Encouraging the child to stand and walk (as far as possible) and keeping the child occupied in learning enjoyable educational and recreational activities usually works well to reduce the chronic pain.

9. **Spasticity** This is the increased resistance to passive movement of the paralyzed limb which, if excessive, can interfere with movement in the bed, and from the bed and with walking. This excessive spasticity is best prevented by proper posititioning to prevent bent hip and 'tip toe' contractures (page 215) and preventing other complications like pressure sores, urinary infections etc.

   In a child with excessive spasms which are getting in the way of functioning, it is necessary first to examine, identify and treat complications like pressure sores, urinary infections, stones in the bladder, chronic constipation, fissures in the rectum etc. These measures usually decrease the spasticity. If they do not, gentle stretching of the 'tight' muscles by standing and walking is usually effective. In case standing and walking are not possible, the tight muscle can be cooled with ice and gently stretched and held in a well padded splint. If the spasms are still not controlled Tablet Diazepam (0.1 mg. per Kg. body weight per day) can be tried in thrice divided doses daily to decrease the drowsiness that this tablet can cause. If this also does not help either then the child should be taken to a competent doctor.

10. **Standing and walking** in the spinal cord injured child will be determined by the extent of paralysis. (see Ch. 59, page 659; Ch. 64, page 703). Children with weakness of the foot only, will need below knee (ankle) braces and crutches. Those with weakness of the knees and hips will require above knee braces and crutches. The training of the child to use the appliances appropriately is crucial for successful walking. Without training to improve strength and endurance, the braces are often discarded. All paraplegic children should be taught to stand and walk in braces.

    Children with weak upper and lower limbs (quadriplegics) may only be able to stand with support. They need to be trained to use a wheelchair. (See Ch. 65, 66, 67- page 715 onwards).

DYSREFLEXIA (Sudden high blood pressure with pounding headaches)

Persons with quadriplegia or very high paraplegia run the risk of 'dysreflexia'-or sudden, dangerous increase in blood pressure with severe pounding headaches.

Dysreflexia is the body's reaction to something that would normally cause pain or irritation , but which the person does not feel because of the spinal cord injury.

COMMON CAUSES OF DYSREFLEXIA

- **bladder problems** - especially when the bladder is too full, infected, or has bladder stones (This is by far the most common cause).
- **stretching of the bowel**-from constipation, with a big ball of hard shit, or from finger pressure to remove the shit
- **pressure areas or sores**- or even irritation from lying on a small object without knowing it
- **burns**
- **spasm of the womb**- especially just before or in the first days of a woman's monthly period, or during childbirth

SIGNS OF DYSREFLEXIA

- severe pounding headache
- sweating of the head
- stuffy nose
- reddish skin patches on face and neck
- goose pimples above the level of injury
- slow pulse
- high blood pressure (up to 240/150)



Dysreflexia is a medical emergency. The high blood pressure could cause fits or deadly bleeding inside the brain.

What to do

Act quickly to remove the cause and lower the blood pressure.

- Quickly lower the blood pressure in the head
  - If lying, sit up; stay sitting until the signs go away.
  - Change position, drop feet down, loosen belt or straps, remove tight stockings.
- Look for the cause of dysreflexia, and remove it if possible.
  - **Bladder**. Feel the lower belly to see if the bladder is full. **If a catheter is in place**,, check for bends or kinks and straighten them to let urine flow. If the catheter is stopped up, open it by injecting 30 cc of boiled and cooled water(or sterile saline solution) into the catheter. If this does not work, take out the old catheter and put in a new one. **If a catheter is not in place** and the person cannot urinate, put in a new catheter and empty the bladder (see p.242).
  - If a **urinary infection** appears to be the cause, inject an anesthetic solution into the bladder through a catheter. Use 10 cc, 1% lidocaine in 20 cc of boiled water. Clamp the catheter for 20 minutes and then release. Treat the infection (see p.248).
  - **Bowel** If the bladder does not seem to be the cause, check for a full bowel. How long has it been since the last bowel movement (shit) ? Put some lidocaine (Xylocaine) jelly on your gloved finger and check if the bowel is packed with hard shit. If it is, put in more lidocaine jelly. Wait for 15 minutes, or until the headache becomes less. Then gently remove the shit with your finger.

- **Pressure**. Change the child's position in order to relieve pressure over bony areas. (Sometimes just staying in the same position too long can bring on dysreflexia).
- If the signs do not go away, get medical help fast as possible.
- If the child has frequent or severe periods of dysreflexia, or you cannot find the cause try to have him seen by a specialist in spinal cord injury, and possibly a 'urologist'(specialist of the urine system)

> ***Suggestion:*** For quadriplegics in villages, it is wise to have injectable 1% lidocaine (Xylocaine) and lidocaine gel and spare urinary catheters available for dysreflexia emergencies.

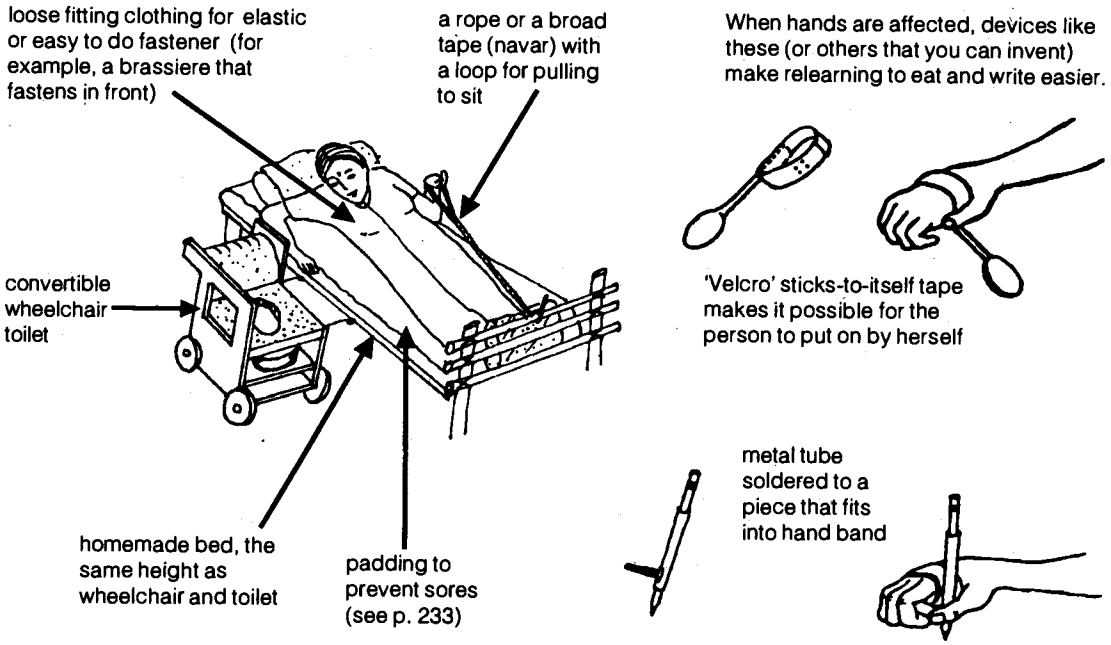
Self-care

With help and encouragement of family, friends and **rehabilitation** workers, the child with spinal cord injury can learn to become as independent as possible in meeting his basic needs: **moving about, eating, bathing, dressing, toileting** and in time **other skills for daily living**.

Progress toward self-care, especially at first, may be slow and frustrating. The child will need a lot of understanding and encouragement. Persons with low spinal cord injury will find it easier to relearn self-care skills than those with higher injuries who have less use of their hands and arms. Quadriplegics usually will remain at least partly dependent on others for some of their daily activities. To make activities easier both for themselves and their helper, it is important that they **avoid getting fat.**

Useful methods and techniques have been worked out for helping relearn basic skills. We cannot describe many of these in detail. However, much depends on determination, imagination, and common sense. Start with first things first-like rolling over and sitting up in bed.

A few **simple aids** can often help a person become more independent. for example,



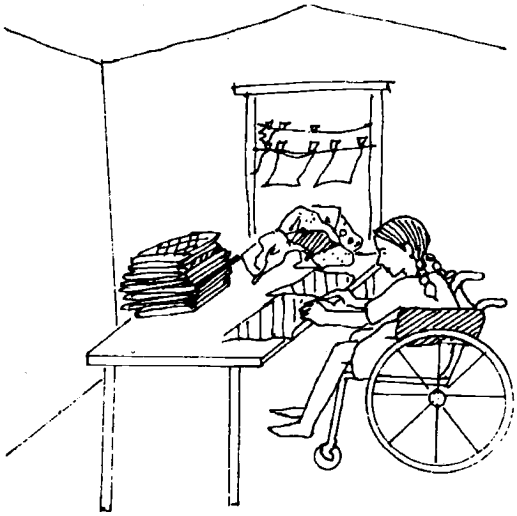
For additional ideas of aids for self-care, see pages 695 to 702. Suggestions for getting in and out of wheelchairs and learning to walk with crutches are included in Chapter 44.

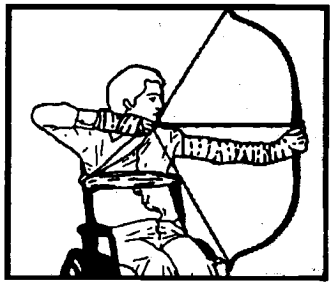
KEEPING ACTIVE



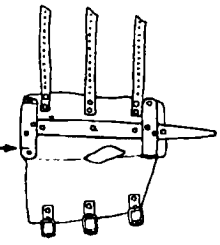
Many of the 'complications' of spinal cord injury happen because the person spends a lot of time lying and sitting. To keep healthy, the body needs to keep active. Lack of movement and activity causes poor flow of the blood. This can lead to pressure sores, swollen feet, painful or dangerous blood clots (thrombosis) especially in the legs, increasing weakness of bones (osteoporosis) with risk of breaking them, stones in the bladder or kidneys, increased risk of urinary infections, and general physical weakness and poor health.

It is important-both for the body and mind-that spinal cord injured persons keep physically active. Let your child do as much for herself as she can: pushing her own wheelchair, bathing, transferring, washing clothes, cleaning house, and helping with work.





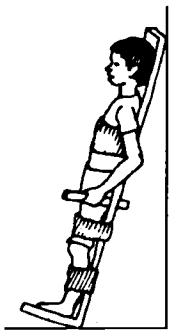
Active games and sports can also be encouraged. **Swimming**, **basketball**, and **archery** can be done well with upper body use only. Quadriplegics can become skillful with bow and arrow by using a straight-arm splint and a special hook, fastened to the hand, to pull the string.



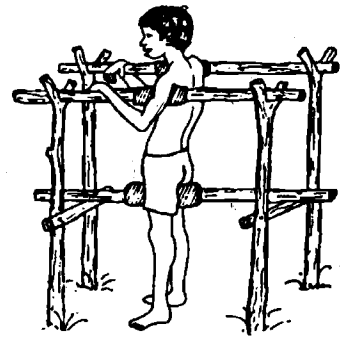
(Note: Archery may also help correct spinal curve. The arm that pulls the string should be on the side with bulge in the back)

> ***Caution:*** care should be taken to avoid archery accidents as it is a major cause of blindness in children.

To keep leg bones growing well and to prevent them from becoming weak and breaking easily, even children who may always be wheelchair riders should stand for a while everyday. Standing also helps the child's bowels move more often and helps to drain the bladder.



This can be done by strapping the child to a standing board or by making some kind of a standing frame. Parallel bars as shown on (Chapter 64, page 579 may be used to train a child to stand and walk.



This standing frame was improved by a paraplegic youth and his father. The boy uses the spasticity in his legs to stand. When the muscles tire he hangs and sits on the padded poles.



The design for a standing wheel-bed allows a spinal cord injured child with pressure sores on her buttocks to actively move about. The child can adjust while on it from a flat-lying position to a near-standing position. It can be made out of wood or metal.



Spinal cord injured persons as leaders

Spinal cord injured persons in various countries are now taking the lead in making new lives for themselves and in getting their communities to recognize their abilities. Examples of a program run primarily by spinal cord injured persons is included in Chapter 56.(see p. 626). Members of this and many similar organizations would be happy to share ideas and suggestions with any group of disabled persons interested in organizing their own program or shop.

OTHER PARTS OF THIS BOOK WITH INFORMATION USEFUL FOR SPINAL CORD INJURY

IMPORTANT: In addition to this chapter, some essential information for spinal cord injury is in other parts of this book, especially Chapter 24, **'Pressure sores"**, and Chapter 25, **"Urine and Bowel Management"**. These chapters are a continuation of information on spinal cord injury. We have put them in separate chapters because the information they cover is also essential for other disabilities.

Chapters marked with a star(*) are **essential for basic care of spinal cord injury.**

*	**Chapter 24**	Pressure Sores
*	**Chapter 25**	Urine and Bowel Management (includes urinary infections).
	Chapter 26	Leprosy (especially p. 264 to 267 on advice for care of hands and feet without feeling)
	Chapter 37	Feeding, especially aids for feeding, p.402 to 404.
	Chapter 38	Dressing
	Chapter 39	Toilet Training, especially aids p.418to 422.
	Chapter 40	Bathing
*	**Chapter 43**	Range-of-motion and Other Exercises
*	**Chapter 44**	Crutch Use, Cane Use, and Wheelchair Transfers
	Chapter 52	Adapting Home and Community to Needs of the Disabled
	Chapter 53	Growing Up, Social Adjustment, Love, Sex, Role in Family and Community
	Chapter 56	Example 3, Centre for the Rehabilitation of the Paralysed
	Chapter 59	Braces
	Chapter 64	Walking Aids
	Chapters 65,66,67	Wheelchairs

For other references to spinal cord injury, see the INDEX, p.784 and the books and reference materials listed on p. 770.

THE STORY OF JESICA

Jesica is a little girl who was paralyzed because of an unnecessary injection she received when she was 3 days old. Her mother does not know why or with what she was injected. This is the story of her rehabilitation at PROJIMO.



The injection resulted in an infection that reached her spine, and permanently paralyzed her legs.

scar from infection →

Misuse of medicines and especially injections is a common and preventable cause of disability. See Chapter 3.



pressure sore

Jesica's feet became clubbed. When she tried to stand, she developed large, infected pressure sores on her knees and feet.

When Jesica first came to PROJIMO at age 4, the village team first treated the infected sores. Then they began to cast her feet to gradually straighten them (see Chapter 61).

(the village team must include a therapist or a plaster technician to ensure proper and correct procedure).



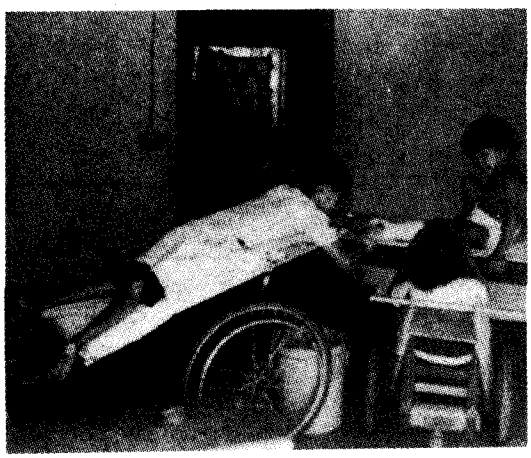


They left 'windows' in the casts to keep treating the sores.

Little by little the sores healed and Jesica's feet straightened. Here one of the workers changes her cast.



Jesica also lacks normal bowel and bladder control. From the uncontrolled loss of urine, she developed pressure sores in her genital area. Vania, an 8-year old paraplegic girl, helped treat Jesica's sores. She also assisted Jesica with a 'bowel program', which helps her 'time' her bowel movements. (see picture on p.250). This makes daily activities and going to school much easier.



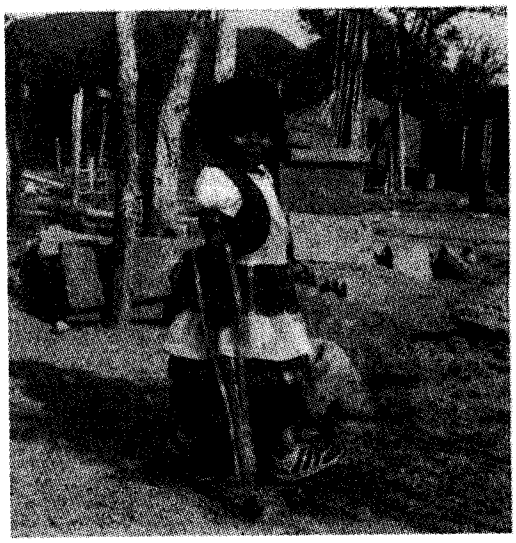
Vania treats the pressure sore on Jesica's foot



Here Vania cleans and dresses sores on Jesica's genital area.



When her feet were straighter, the village workers made above-knee braces for her and a simple wood walker. In a few weeks Jesica was walking.



With practice Jesica was able to walk with crutches- and finally with only her braces.

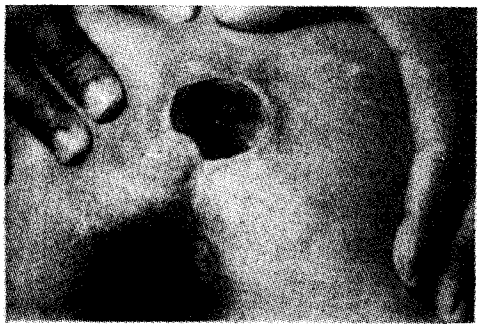
Jesica now goes to school in the village. Seeing disabled persons at PROJIMO who were happy,active and accepted in the community has given Jesica a more hopeful, confident, and adventurous outlook on life.



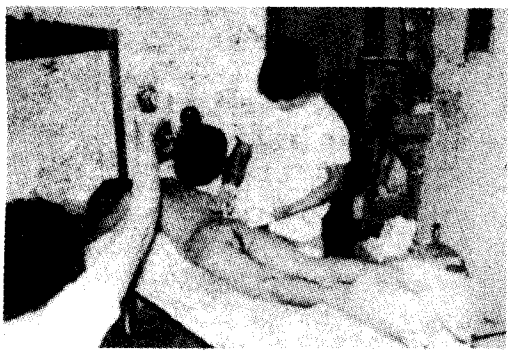
Mari, who is paraplegic is one of the leaders of the PROJIMO team. Here she works on a cast for making a plastic brace.



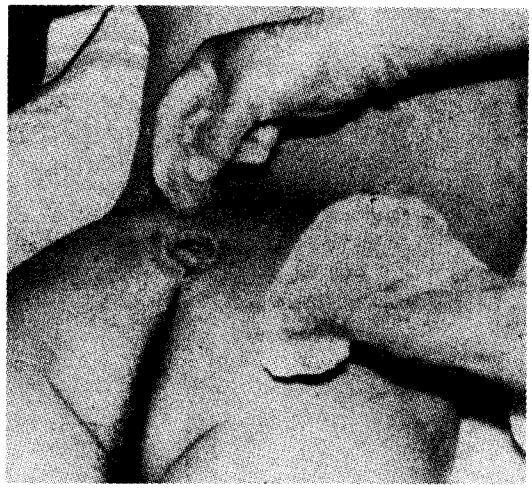
Victor, a young doctor became quadriplegic in a traffic accident. He could do nothing for himself when he came to PROJIMO. The village workers helped him gain strength and develop many skills. Soon he became a member of the PROJIMO team and became the village doctor.



This pressure sore, at the base of the spine in a young man with quadriplegia was present for 2 years. It was 15 cm across under the skin, and had completely destroyed the lower part of his spine.



Village workers at PROJIMO clean and dress the pressure sore.



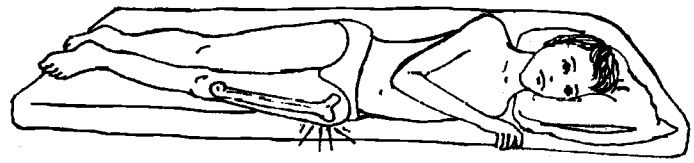
Here one of the workers packs the sore with a paste of sugar and honey. With this treatment 2 times each day, the sore stayed clean and free of infection, and healed rapidly (in about 6 months).

NOTES

CHAPTER **24**

Pressure Sores

WHAT ARE THEY?



This is a common pressure sore point-over the top of the thigh bone.

Pressure sores, or 'bed sores', are sores that form over bony parts of the body when a person lies or sits on that part of the body for too long without moving. Where the skin is pressed against the bed or chair, the blood vessels are squeezed shut so that the blood cannot bring air to the skin and flesh. If too much time passes without moving or rolling over, the skin and flesh in that spot can be injured or die. First a red or dark patch appears. And if the pressure continues, an open sore can form. The sore may start on the skin and work in. Or it may start in deep near the bone and gradually work its way to the surface.

Who is likely to get pressure sores?

When a normal healthy person lies or sits in one position for a long time, it begins to feel uncomfortable, or to hurt. So she moves or rolls over, and pressure sores are avoided. People most likely to get pressure sores are:

1. persons who are so **ill, weak,** or **disabled** that they cannot roll over by themselves. This includes persons ***severely disabled*** from **polio, brain damage, advanced muscular dystrophy,** or **a bad injury.**

2. persons who **have no feeling** in parts of their body, who do not feel the warnings of pain or discomfort when their body is being damaged. This includes persons with **spinal cord injury, spina bifida,** and **leprosy.**

> ***WARNING:*** **Because persons with spinal cord injury are at first unable to turn over, and also have lost the ability to feel in parts of their bodies, they are at very high risk for pressure sores.**

3. persons who have a **plaster cast** on an arm or leg (to correct a ***contracture*** or to heal a broken bone), when the plaster presses over a bony spot. At first the pressure will hurt and the child may cry or complain. But in time the spot will grow numb and the child will stop complaining – although a sore may be forming.

   The risk is greater when using casts on children who have no feeling in their feet. On these children, even a corrective shoe or brace can easily cause a pressure sore-unless great care is taken.



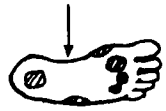
Casts to straighten contractures and clubbed feet must be very well padded over bony places to prevent pressure sores.

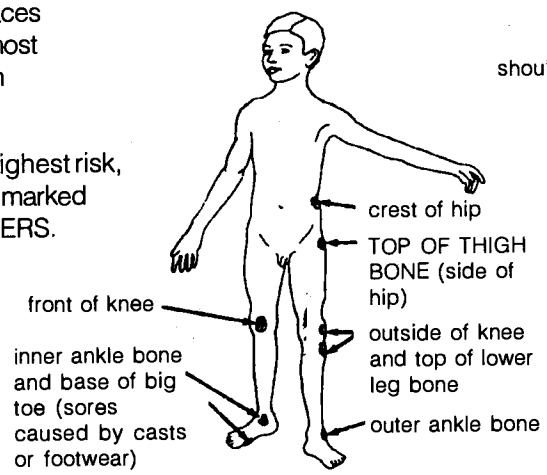
Where are pressure sores most likely to form?

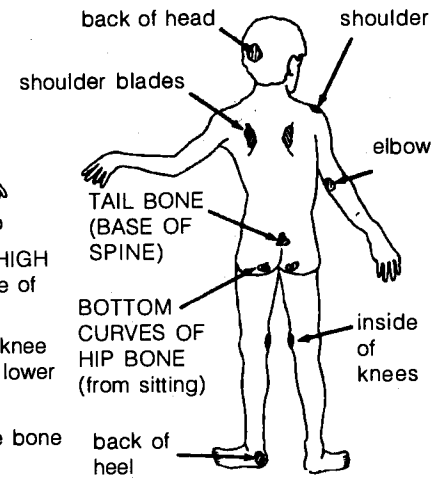
They can form over any bony area. The places where they form most often are shown in the pictures.

The points of highest risk, all on the hips, are marked in CAPITAL LETTERS.

common sites of sores in feet that have lost feeling







How dangerous are they?



Pressure sores, if not very carefully cared for, can become large and deep. Because they contain dead skin and flesh, they easily become ***infected.*** If a sore reaches the bone, which it often does, the bone can also become infected. Bone infections are often very hard (and costly) to cure, may last for years, and may keep coming back, even after the original pressure sore has healed. (See "Bone Infections," Chapter 19.) Bone infections can lead to severe disabling deformities.



These pressure sores in a 15 years-old girl who is quadriplegic were treated with honey and sugar and healed in 2 months. (See p.237) PROJIMO.

Infections in deep pressure sores often get into the blood and affect the whole body causing fever and general illness. This can lead to death. In fact, **pressure sores are one of the main causes of death in persons with spinal cord injury.**

In persons with high spinal cord injuries (quadriplegia) the irritation from pressure sores can also bring about sudden severe headaches and high blood pressure (dysreflexia, see p.218), which can also cause death.

How common are pressure sores?

In persons who have lost feeling in parts of their body, pressure sores are **very common.** Most spinal cord injured persons in rich countries, and nearly all in poor countries, develop pressure sores. Often the sores start in hospitals shortly after the back injury, due to **inadequate nursing care.** Therefore, it **is important that families of spinal cord injured persons, and the persons themselves, learn as early as possible about the prevention and early treatment of pressure sores, and take all the needed steps.**

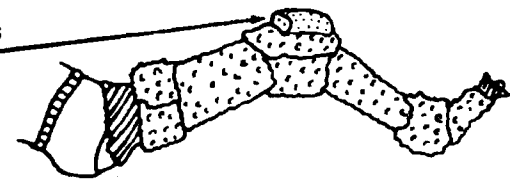
PREVENTION OF PRESSURE SORES

It is important that both the child and family learn about the risk of pressure sores and how to prevent them.

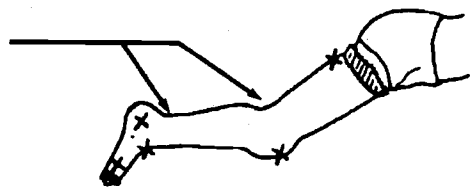
- **Avoid staying in the same position** for very long. **When lying down, turn** from side to side or front to back at least every 2 hours (or up to 4 hours if padding and cushioning are excellent). When **sitting,** lift body up and change position every 10 or 15 minutes.
- Use **thick, soft padding,** pillows, or other forms of cushion arranged so as to protect bony areas of the body. (For cushion designs, see p.233 and 234)
- Use **soft, clean, dry bed sheets.** Try to avoid wrinkles. Change bedding or clothing every day and each time the bedding gets wet or dirtied. **A person who stays wet gets pressure sores – especially if it is from urine.**
- **Bathe** the child daily. Dry the skin well by patting, not rubbing. It is probably best not to use body creams or oils, or talc, except on the hands and feet to prevent cracking, as these soften the skin and make it weaker. *Never* use heat-producing oils, lotions, or alcohol.
- **Examine the whole body** carefully every day, checking especially those areas where sores are most likely to occur. If any redness or darkness is present, take added care to prevent all pressure over this area until the skin returns to normal.
- **Good nutrition** is important for preventing pressure sores. Be sure the child gets enough to eat (but do not let her get fat). Give her plenty of fruits, vegetables, and foods with protein (beans, lentils, eggs, meat, fish, and milk products.) If the child looks pale, check for signs of anemia (see p.392) and be sure she gets iron-rich foods (meat, eggs, and green leafy vegetables) or takes iron pills (ferrous sulphate) and vitamin C (oranges, lemons, tomatoes, etc.)
- As much as is possible, the child should learn to examine her own body for pressure sores every day and take responsibility for all the necessary preventive measures herself.

Other precautions

- To avoid pressure sores or other injuries on feet that do not feel, use well-fitted, well-padded sandals or shoes. These and other precautions are discussed under "Spina Bifida" (p.201) and "Leprosy" (p.266).
- To avoid pressure when straightening limbs with casts, put extra padding over bony spots before casting and do not press on these spots as the cast hardens. Listen to the child when he says it hurts, and check ***where*** it hurts.



If it hurts in these spots, it is probably the tight cord *(tendon)*. A little pain is normal with stretching, but if it hurts a lot, examine it.



If it hurts in one of the spots marked with an X, it may be a pressure sore. Remove the cast and see.

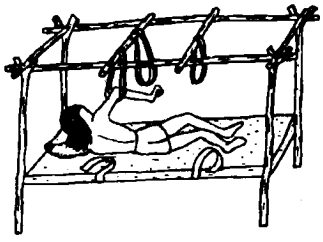
Changing position

When a child has recently had a spinal cord injury, he must be turned regularly, taking great care not to bend his back. After every turn, check the bony prominences for redness or early signs of a sore.

One good way is to roll him over using a sheet under him *like* this.



As the child gets stronger, hang loops and provide other aids, if needed, so she can learn to turn herself.





At first it is important that the person turn, or be turned, at least **every 2 hours,** day and night. When the child has high fever, he or she may require to be turned more frequently. Later, if there are no signs of pressure sores, the time between turns can gradually be lengthened to **4 hours.** To avoid sleeping through the night without turning, an alarm clock can be a big help.

When the child begins to sit or use a wheelchair, there is a new serious danger of pressure sores. **The child must get into the habit of taking the pressure off his bottom every few minutes.**

Amit has strong arms. He can lift up his whole body and hold it up for a minute or two. This lets the blood circulate in the bottom.



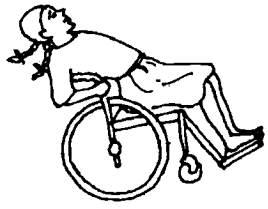
Joseph's arms are weak. He takes the pressure off his bottom by leaning his whole body over the armrest, first on one side, and then on the other.



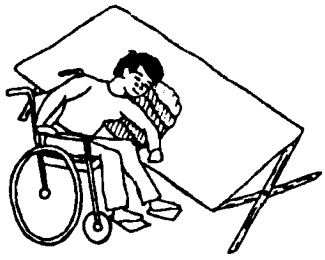
When doing this, one buttock lifts in the air.



Namita has a wheelchair with a low back, so she can lean back and lift her hips off the seat.



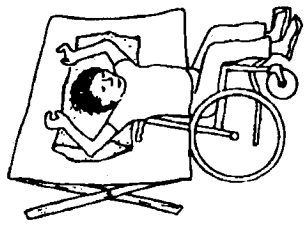
If the chair has no armrests, or they can be removed, the child can lie sideways over a pillow on a high bed. He can rest for 15 to 30 minutes like this.



If he has very little arm and body control, he can put his feet on the floor (with help if needed) and lean forward with his chest on his knees. This takes the pressure off his bottom.



Or have someone tip his chair backward for one minute or more. For a longer 'nap' that rests the bottom, someone can tip his chair backward onto a cot.



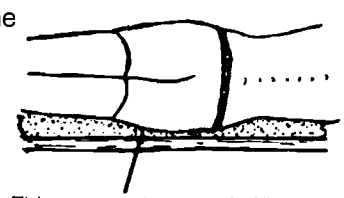
To prevent pressure sores when sitting, take the weight off your butt for one whole minute at least once every 15 minutes!

Padding and cushions for lying

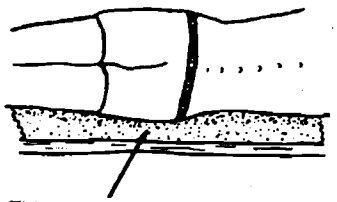
To prevent pressure sores, it is essential that the person who has lost feeling lie and sit on a soft surface that reduces pressure on bony areas.

- It is best to lie on a flat surface with a **thick, spongy mattress.**

A thick **foam rubber** mattress often works well. However, some foam is so spongy that it sinks completely down under weight. Then the bony area is not protected from the hard board. A firm sponge with very small air bubbles **(microcell rubber)** works well, but is expensive.



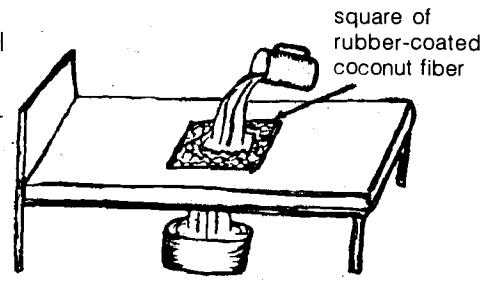
This sponge is too soft. The hip bone is pressed against the board below.



This sponge is better. It is firm enough to keep the hip bone of the board below.

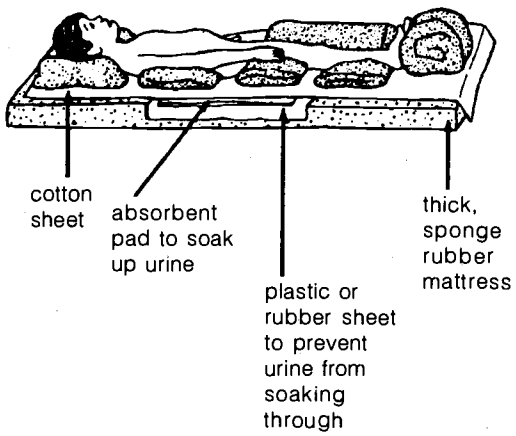
A 'waterbed' (bag-like mattress filled with water) or air mattress also works well.

In some countries, an excellent mattress material is made of rubber-coated coconut fiber. Urine can be washed out by pouring water through it. Because this material is costly, a ***rehabilitation*** program in Bangladesh cuts a square out of a cheap mattress and fits in a square of the coconut fiber sponge.

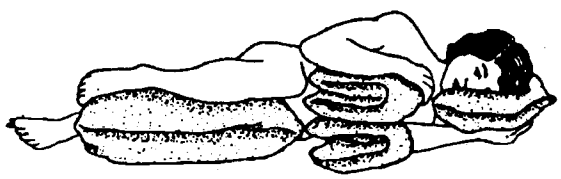


- Careful placement of **pillows,pads, or soft, folded blankets** can also help prevent pressure sores. These are especially important in the first weeks or months after a spinal cord injury when the person must lie flat and be moved as little as possible. Pillows should be placed to avoid pressure on bony places, and to keep the person in a position that is healthy and that helps prevent contractures.

BACK-LYING

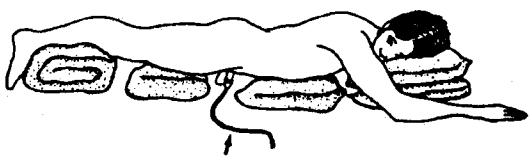


SIDE-LYING



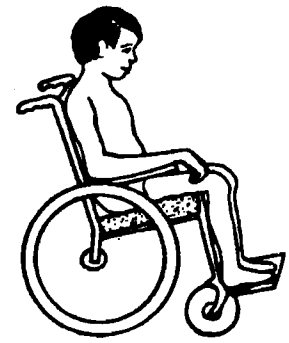
For self-placement of pillows, seep.215.

BELLY-LYING



urine collection tube (See p.240)

Chair and wheelchair cushions

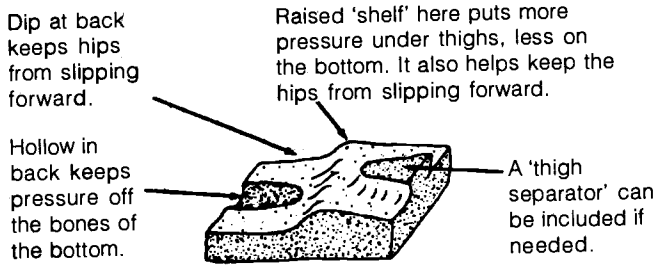


For the child who has lost feeling in his bottom, the type of seat cushion he uses is very important–especially if his ***paralysis*** makes it difficult to lift up or change positions.

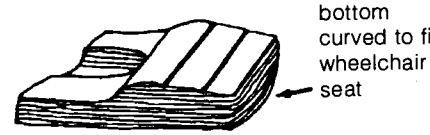
All spinal cord injured persons should use a good cushion. Sitting directly on a canvas or a poorly padded wood seat causes pressure sores.

Special cushions are made with 'soft spots' of an almost-liquid ' silicone gel' in the areas of greatest pressure. However, these cushions are very expensive. Also, the gel may get too soft and liquid in hot weather.

Good cushions can be made of **'microcell' rubber,** which is fairly firm. It works best if it is cut and shaped to reduce pressure on bony areas:



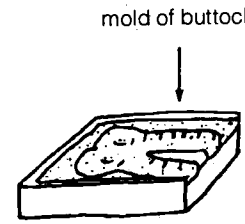
A good, low-cost way to make a fitted cushion is to build a base out of many layers of **thick cardboard** glued together. Cover it with a 2 or 3 cm. thick layer of sponge rubber.



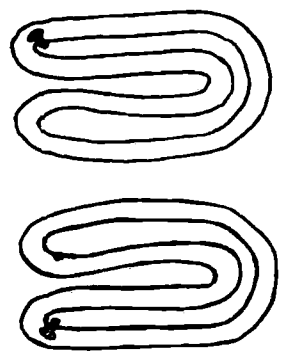
Wet the cardboard and sit on it wet for 2 hours, so it forms to the shape of the butt. Then let it dry, and varnish it.

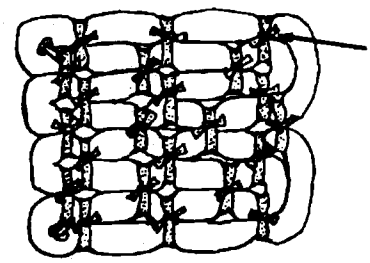
Before making a specially-fitted cushion, you can make a 'mold' of the person's bottom by having him sit in a shallow container of soft clay, mud, or plaster. Note the bony hollows and form the seat to fit them.





Air cushions made from **bicycle inner tubes** are excellent for prevention of pressure sores, and for bathing on a hard surface. Use 1, 2 or more tubes, depending on size of tube and size of child.





Bind loops of the tubes together with think straps of inner tube.

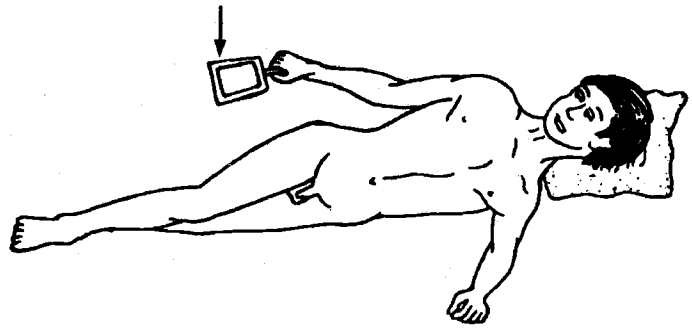
Pump in enough air so that the whole bottom is held up by air.

(Idea from wheelchair rider-builders at Tahanan Walang Hagdanags House With No Stairs, Quezon City, Philippines).

TREATMENT OF PRESSURE SORES

Watch for the first signs of a pressure sore by examining the pressure prone sites after each turn, initially and later the whole body every day, teach the child to do this using a mirror

If early signs of a sore appear (redness, darkness, swelling, or open skin), change body position and use padding to protect that area from pressure.



For large areas (like the bones near the base of the spine, get the child to lie on her face.

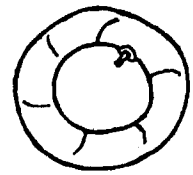
Early signs of a sore are local increase in temperature and redness that does not blanch with pressure. If care to avoid pressure is not taken immediately, the skin will break down and a sore will form.

WARNING: For small areas such as heels, *never* use a ring or 'donut' of cloth to keep weight off the sore. This can cut off blood supply to the skin inside the ring and make the sore worse.



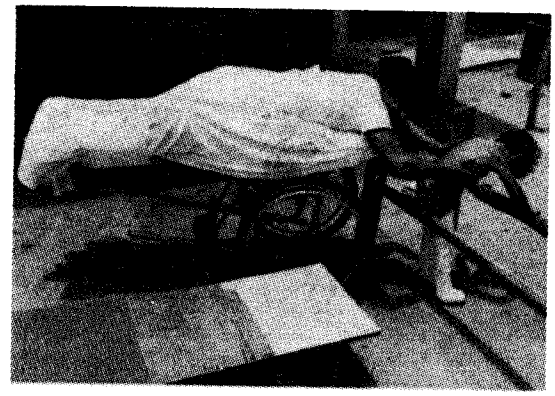
NO

Do not try using small (motor scooter) inner tube to keep weight off the sore area. (Sweaty skin against the rubber can also cause sores). These just cause larger sores to develop



IF A PRESSURE SORE HAS ALREADY FORMED:

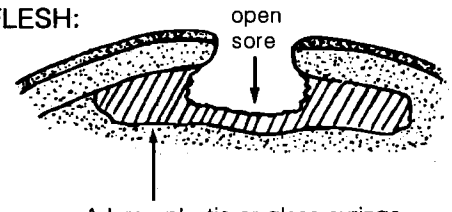
- **Keep pressure off the sore area** completely and continuously
- **Keep the area completely clean.** Wash it gently with clean or boiled water twice a day. Do *not* use alcohol, iodine, merthiolate, or other strong antiseptics.
- **Eat well.** If lots of liquid comes out of the sore, a lot of protein and iron are lost with it. These must be replaced for quicker healing. Also take iron pills if signs of anemia are present. Eat foods rich in protein: beans, lentils, eggs, peanuts, meat, fish, milk products.



This paraplegic young man has a large pressure sore on his bottom. Until it heals, he must not sit. Village rehabilitation workers made this wheel lying card for him to move about on. Here he helps a boy learn to walk. (Photo, John Fago).

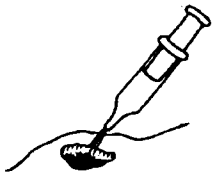
- **Do not rub or massage** areas where pressure sores might be forming. This could tear weakened flesh and make the sore inside bigger.
- Once the child has one sore, he is likely to develop more sores because there are fewer positions for him to lie on safely, so greater ***CAUTION*** is required.

IF A SORE IS DEEP AND HAS A LOT OF DEAD FLESH:



A large plastic or glass syringe works well for washing out the sore. Wash the syringe well with soap and water after each use.

- Clean the sore 3 times a day.
- Each time, try to scrape and pick out more of the dead rotten flesh. Often, you will find the sore is much bigger inside than you first thought. It may go deep under the edges of the skin. Little by little remove the dead flesh until you come to healthy red flesh (or bone!).
- Each time after cleaning out the dead flesh, wash the sore out well with soapy water or Hydrogen Peroxide. Use liquid surgical soap if possible. Then rinse with clean (boiled and cooled) water.



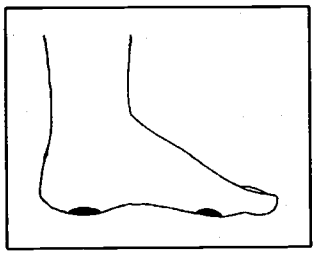
Dead flesh-may be gray, black, greenish, or yellowish. It may have a bad smell if infected.

If the sore is infected (pus; bad smell; swollen; red;hot area around the sore; or the person has fevers and chills):

- Clean out the sore 3 times a day as described.
- If possible position the child such that the pus drains out of the wound twice or thrice daily.
- If possible, take the person to a 'clinical laboratory' where a sample from the sore can be removed and cultured' to find out what germs are causing the infection and what medicine is most likely to fight it well.
- If a 'culture' is not possible, try treating the person with penicillin, tetracycline, or (if possible) dicloxacillin.
- Follow the advice of an experienced lealth worker.

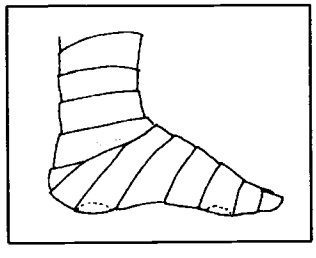
If the sore does not get better, or keeps draining liquid or pus from a deep hole, the bone may be infected. In this case, special studies, treatment, and possible surgery may be needed. Try to take the person to a capable medical center. (See Chapter 19).

However, in some children with a deep chronic sore in the heel or sole, who have no fever or swelling of the glands in the groin, the sore will heal if all pressure is relieved. This can be done by dressing the sore and applying a plaster of paris cast on the foot and ankle. A Bohler Iron can then be applied to transmit froces from the ground to the knee, thus avoiding further injury to the pressure sore.



deep sore under metcarpal head

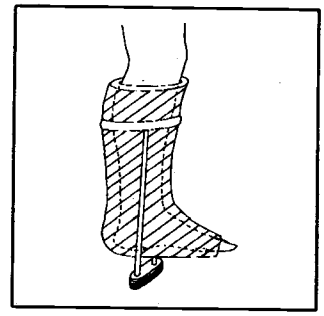
deep sore in the heel, but no evidence of spreading infection



Then apply a plaster of paris cast over the padding



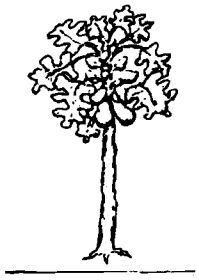
after applying a gauze dressing, wrap the limb with cotton padding



Bohler Iron attached to the POP (plaster of paris) cast with more POP to completely "rest" the heel and sole.

The child is then asked to walk with crutches. When the cast is soaked through or after a month, the cast can be removed. It the sore has not healed it can be recast for another month. Great care must be taken to ensure that the cast does not produce any new sores by being too tight. When not walking, the child should elevate the foot so that it is at the same level as his chest. This technique can be used to heal very resistant foot sores

Two folk treatments that help in curing pressure sores



PAPAYA

Papaya has chemicals (enzymes) that digest dead meat. Cooks use it to soften meat. The same chemicals can help soften the dead flesh in a pressure sore, and make it easier to remove.

First clean and wash out a pressure sore that has dead flesh it. Then soak a sterile cloth or gauze with 'milk' from the trunk or green fruit of a papaya plant and pack this into the sore. Repeat cleaning and repacking 3 times a day.

HONEY AND SUGAR

Once a pressure sore is free of dead flesh, **filling it 2 to 3 times a day with honey or sugar** helps prevent infection and speeds healing. This treatment, used by the ancient Egyptians, and recently rediscovered by modern doctors, works remarkably well. It is now being used in some American and British hospitals.

To make filling the sore easier, mix honey with ordinary sugar until it forms a thick paste. This can easily be pressed deep into the sore. Cover the sore with a thick gauze bandage.



A village rehabilitation worker treats a young man's pressure sores with a paste made by mixing honey and sugar.

CAUTION: **It is important to clean out and refill the sore at least 2 times a day. if the honey or sugar becomes too diluted with liquid from the sore, it will feed germs rather than kill them.**

Molasses can also be used. In Colombia, South American doctors shave thin pieces off blocks of raw sugar and put these into the sore.

NOTES

Urine and Bowel Management

CHAPTER **25**

With Spinal Cord Injury and Spina Bifida

Most persons with ***spinal cord*** injury or spina bifida do not have normal ***bladder*** or ***bowel*** control (control for urinating passing stool). This loss of control can be inconvenient, embarrassing, and cause social and emotional difficulties. Also, the loss of control can cause skin problems and dangerous urinary *infections*. For these reasons, it is important to learn ways to stay clean, dry, and healthy. Most of the methods are not difficult, so even children should be able to do it themselves. This will help them feel more self-reliant.

URINE MANAGEMENT

The main goals of urine management are:

1. to prevent urinary infection, and

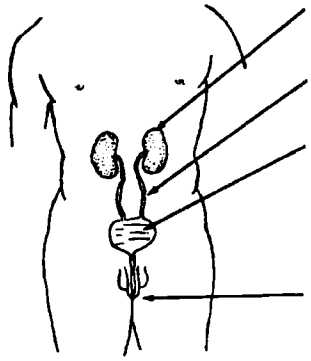
2. self-care in staying as dry as possible.

Prevention of urinary infection, is extremely important. **Infections of the urinary system (bladder and kidneys) are very common in both spinal cord injury and spina bifida, and are one of the main causes of early death.** Therefore, any method used for self-care or staying dry must also help prevent urinary infections. Make every effort to prevent germs from getting into the bladder. **Keeping clean is essential.** Also, it is important to empty the bladder regularly as completely as possible. If some urine stays in the bladder, bacteria will grow in it and cause infection.

> The ideal method of urine control empties the bladder completely and in a clean, regular, easy, and self-reliant way.

Different methods work best for different persons-depending mostly on what 'type' of bladder a person has. We discuss this on the next page.

THE URINARY SYSTEM

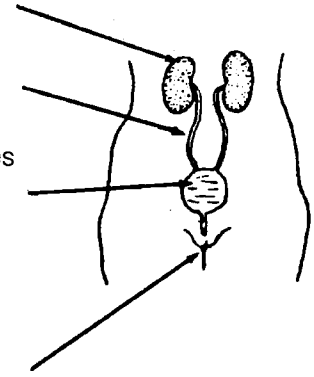


The **kidneys** take waste from the blood, producing urine.

The **ureters** carry the urine to the bladder.

The **bladder** is a bag that stretches to store the urine and empties it when it gets full.

The urine passes from the bladder through the 'urethra' and comes out through the penis in boys and through a small opening between the lips of the vagina in girls.



'Types' of bladder – in persons whose feeling and control have been partly or completely lost.

AUTOMATIC BLADDER *(Spastic bladder):* A person with ***paralysis*** whose legs have 'reflex spasms' (uncontrolled stiffening or jerking) usually also has reflex spasms in his bladder. As the bladder fills with urine, the walls of the bladder stretch and cause a reflex spasm. As the bladder squeezes, the muscles that hold back the urine relax, letting the urine flow out. This is called an 'automatic bladder' because it empties automatically when it gets partially full.

LIMP BLADDER *(flaccid bladder):* When a person's paralyzed legs are limp and do not have spasms, usually the bladder is also limp, or flaccid. No matter how much urine fills the bladder, it will not squeeze to empty. The bladder stretches until it cannot hold any more and the urine begins to drip out. The bladder does not completely empty this way. Some urine stays in the bladder, increasing the chances of infection,as explained earlier.

The most simple methods of bladder management work well with an automatic bladder but do not work with a limp bladder. **So try to figure out which type of bladder a child has.**

For the first few days or weeks after the spinal cord has been injured, the bladder is almost always limp. Urine either drips out or does not come out at all. Then, as the 'spinal shock' wears off, persons with higher back injuries (above the 2nd lumbar vertebra, see p. 204) usually develop automatic bladders. In persons with lower back injuries, the bladder usually stays limp.

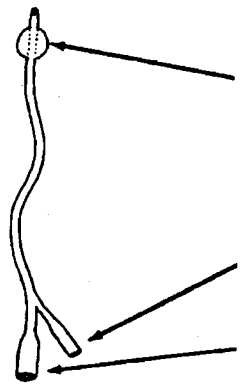
During the first week usually a 'Foley's catheter' is kept in the bladder all the time. However, after about 1 to 2 weeks, it is a good idea to test how the bladder works by removing the catheter and trying one of the methods described in this chapter. If the person is often wet, try another method for that type of bladder.

A **catheter** is a flexible rubber tube used for draining urine out of the bladder.

Standard catheter



Foley catheter



A 'Foley' catheter has a small balloon near the tip. This balloon is filled with water when it is inside the bladder, so that it can be left inside and will not slip out.

Water is injected into the balloon here.

Urine drains out here.

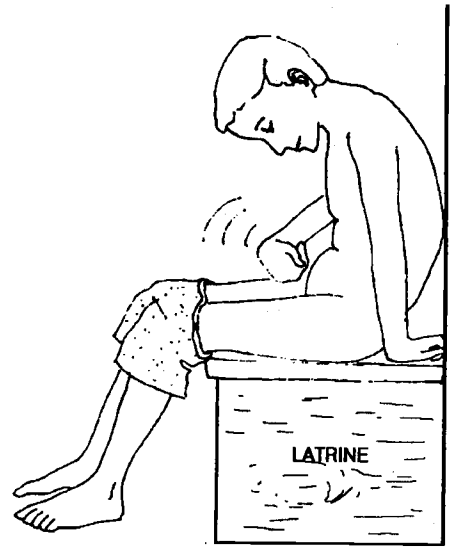
For instructions on how to use a catheter, see p. 242.

Methods for automatic bladder

1. **TRIGGERING:** This method usually causes the bladder-emptying reflex to work when the person is ready to urinate. It can be done using a urinal, toilet, potty or jar. **This is the first method to try** because nothing is put into the bladder. It is easy, so a child can do it alone.

- Tap the lower belly (over the bladder) firmly with your hand for about 1 minute. Stop and wait for the urine to come.

- Tap again. Repeat several times until no more urine flows.



If possible, once a week after triggering use a catheter to see how much urine is left. If there is less than a cupful (150 cc.), continue the triggering program. If there is more than a cupful on several occasions, then the bladder is not emptying well enough. Try another method.

2. **PERIODIC USE OF A CATHETER:** This method allows the bladder to be emptied completely before becoming too full. Sometimes it can be used to prepare the body for triggering. Put a clean or sterile standard catheter into the bladder every 4 to 6 hours to empty the urine.

For instructions on how to put in a catheter, see the next page.

> *CAUTION:* If you drink more liquid than usual, put in the catheter more frequently to keep the bladder from stretching too much.

If urine drips out between catheter times, boys can wear a condom (see p. 245) and girls a large sanitary pad or *diaper* to catch the urine. To prevent infection, change these each time you use the catheter and wash the penis or the skin around the vagina with soap and water.



How to put in a catheter

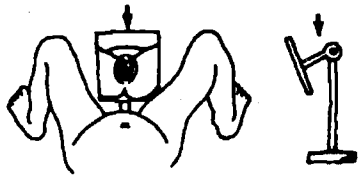
Health workers and parents can easily be taught to put in a catheter. With a little practice, paraplegic and some quadriplegic children can also learn to put the catheter themselves.

Note: The best catheter size is usually either 8 or 10 for a small child to even 16 for a bigger child.



Children as young as age 5 can learn to catheterize themselves.

mirror side view



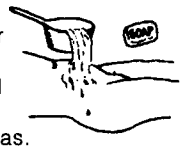
A mirror can help girls to find the urine hole.

STERILE CATHETERISATION

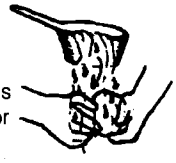
1. If possible boil the catheter (and any syringe or instrument you may be using) for 15 minutes.



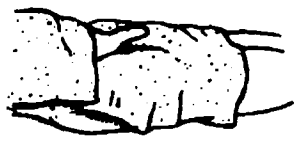
2. Bathe well (at least daily). Wash well under foreskin or between vaginal lips and surrounding areas.



3. Wash hands- with soap (like Betadine). After washing touch only things that are sterile or very clean.



4. Put very clean cloths under and around the area.



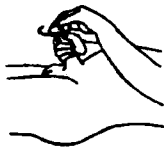
5. Put on sterile gloves- or rub hands well with alcohol or surgical soap.



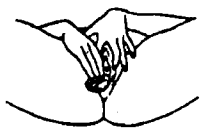
6. Cover the catheter with a lubricant (slippery cream) like ***K-Y Jelly*** that dissolves in water (not oil or ***Vaseline***).



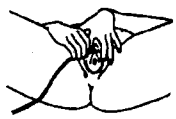
7. Pull back foreskin or open the vaginal lips,



and wipe the urine opening with a sterile cotton soaked with surgical soap.



8. Holding the lips open or the foreskin back, gently put the catheter into the urine hole. Twist it is as necessary but DO NOT FORCE IT





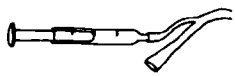
Hold the penis straight at this angle

9. Push the catheter in until urine starts coming out-then 3 cm. more.



10. A.If using a regular catheter, each time you urinate tighten your stomach *muscles* or gently massage the lower belly to empty all urine. Then take out the catheter, wash it well, boil it, and store it in a clean jar or towel.

10B. If using a Foley (permanent) catheter, inject 5 cc. of sterile water into the little tube, to fill the balloon (or up to 10 cc. if it is a 30 cc. Foley), and connect the bigger tube to the collection tube or leg bag.



Change the catheter every 2 weeks (or more often if there is an infection).



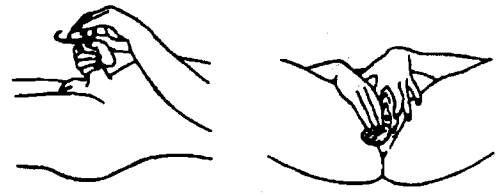
CAUTION: **Most catheters can be boiled and reused many times, for about a month. But throw it away if it begins to get hard or brittle or infection sets in.**

The great care with cleanlines shown in the previous page (boiling the catheter, wearing gloves) is important when using a fixed (Foley) catheter. However, for periodic use of a regular catheter, a clean rather than sterile technique is more practical (and therefore may be safer).

CLEAN INTERMITTENT CATHETERISATION : This can be done by a parent or the child.



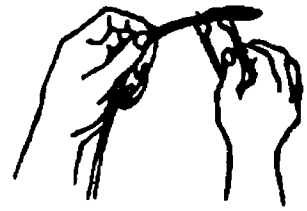
1. Wash hands with soap and water



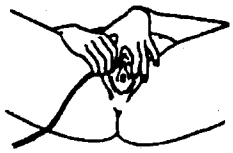
2. wash penis/vaginal lips and surrounding area with soap and water. Pull back the foreskin or open the vapinal lips and wash.

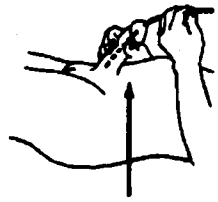


3. Wash catheter (both inside and outside) with running water



4. Apply a lubricant (2% lignocaine gel) over the tip of the catheter





5. Holding the lips open the foreskin back, gently put the catheter into the urine hole. Twist if necessary. DO NOT FORCE IT. This can be done in the lying or sitting positions.

7. When the urine begins to flow, wait until all flow stops before withdrawing the catheter. Withdraw the catheter slowly so that all the urine drains out. Gentle pressure over the lower belly can also ensures complete emptying of the bladder.



6. When the urine to flow, wait until all flow stops before withdrawing the catheter. Withdraw the catheter slowly so that all the urine drains out. Gentle pressure over the lower belly also ensures complete emptying of the bladder.



7. Wash the catheter and store it vertically in a cloth bag so that it drips dry! This will minimise infection.



8. Wash hands again.

3. FOLEY CATHETER : *(fixed catheter):* With this method, the catheter is left in all the time to drain the urine from the bladder continuously. A Foley is often used immediately after injury, and in some cases, for many months or years. The catheter connects to a collection bag that can be attached to the leg and worn under the clothes.

In many areas this is the easiest method because other supplies are difficult to get. However, a Foley can cause many problems, including:

- Bacteria can get into the bladder, causing a infection, which can lead to fever, kidney damage and even death.
- **Continuous bladder irritation** can cause bladder stones to form.
- The catheter may even cause a **sore on the underside of the penis** through which urine leaks. This may need surgery to correct.

If you have tried other methods unsuccessfully or no other equipment is available, a Foley catheter may be the only choice. To prevent complications it is **very important that it be used carefully:**

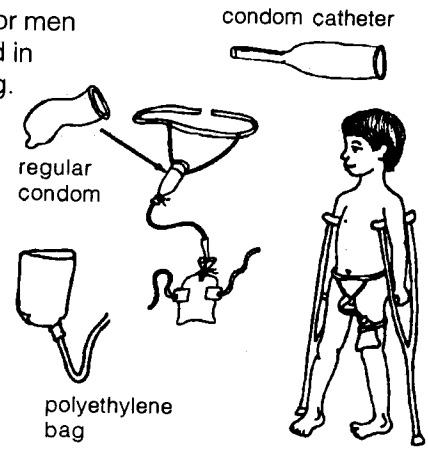
- Always wash your hands well before touching the catheter.
- Clean the skin around the catheter with soap and water at least twice a day and after each bowel movement.
- Do not disconnect the collection bag except to empty and wash it. Wash it out with soap or bleach (***Clorox***) once a day.
- If the catheter must be clamped, use a sterile plug, ***never*** a glass ampule (small bottle). It may break and cause injury.
- Always keep the collection bag below the level of the bladder to keep the urine from flowing back.
- Tape the catheter to the leg when in a wheelchair. Boys should tape the catheter on the belly when lying down.
- Check regularly to make sure the urine is emptying and that the catheter is not plugged up. Avoid sharp bends or folds in the tubing which may cause blockage.
- When turning, lifting, or moving the person, remember to move the bag too. Do not let it pull at the catheter or stay under the person.
- When the bag gets filled to 2/3 remember to empty it.
- If the catheter gets plugged up, take it out, squirt boiled water through it, and put it back. Or use a new one. In emergencies, you can squirt a little (cool) boiled water back through the catheter while it is in place. Use a sterile or very clean syringe.

4. CONDOM CATHETER: This is a practical method for men and boys who cannot control their urine. It can be used in combination with triggering, to avoid accidental wetting.

A condom catheter is a thin rubber bag that fits over the penis. It has a tube that connects to a collection bag. They come in different sizes.

If condom catheters are too costly or not available, a regular condom ('rubber', 'sheath', or 'prophylactic' for family planning) can be attached to the collection tube with a rubber band or tape.

Or a thin, very clean plastic bag can be used. Or, on a child, use the finger of a rubber glove (or a 'fingercot').

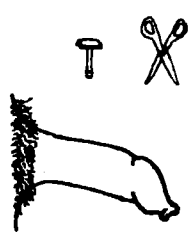


CAUTION: DO NOT USE THE CONDOM USED BY ONE PERSON ON ANY OTHER PERSON EVEN AFTER BOILING.

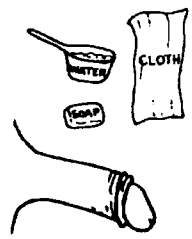
To hold the condom on the penis, a special very stretchy adhesive tape can be used as shown in this series of drawings.

How to put on a condom using *Con-stay* tape

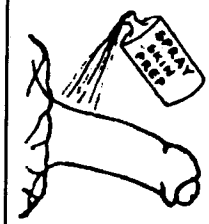
Warning: Use only Con-stay or another easily stretchable adhesive tape. (Ordinary adhesive tape can stop blood flow when the penis swells.)

1. 

Cut off hair.

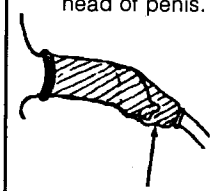
2. 

Pull back skin. Wash with soap and water and dry well.

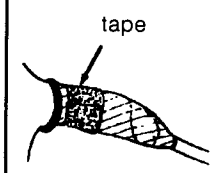
3. 

Apply 'skin prep' (tincture of benzine) to help condom stick to skin.

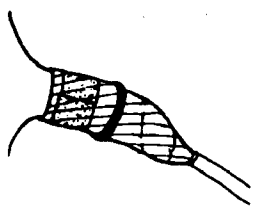
4. Pull foreskin forward over head of penis.



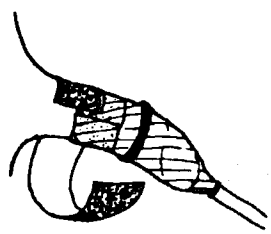
Roll on condom leaving some space here.

5. 

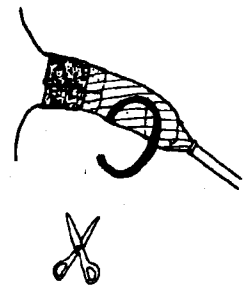
Loosely wrap *Con-stay* tape around condom so it sticks to itself.



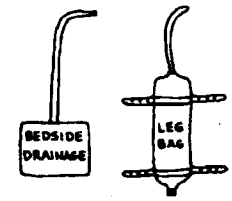
Roll the condom back over the tape.



Add a second strip of tape, 1/2 on the condom and 1/2 on the skin.

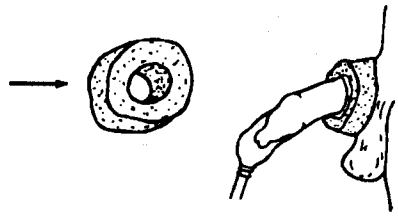


Cut off the rubber rim.



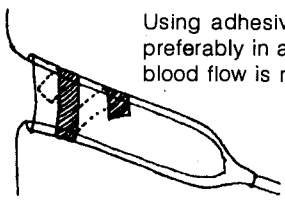
Connect condom to leg bag.

One of the safest and cheapest ways to hold a condom on the penis is to cut a ring out of soft foam rubber. Pass the condom under the ring and turn it back over it.

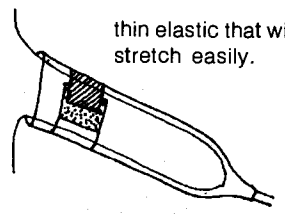


The ring can be used again and again.

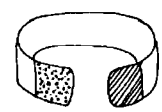
Another method of affixing the condom is



Using adhesive (Elastoplast) preferably in a spiral so the blood flow is not stopped.



thin elastic that will stretch easily.



Velcro to bring the ends together without stretching the elastic, around the base of the penis.

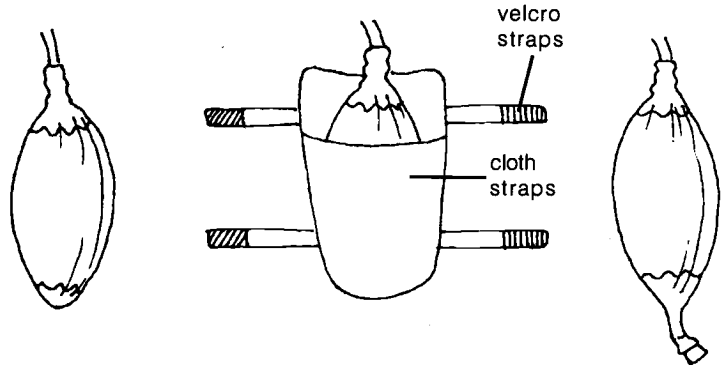
(This is useful in Tetraplegic patients who find it difficult to use their hands.)

WARNING

The condom should be removed at least once every day and the penis washed and *DRIED* .Only then should the condom be re-applied. If there is any sore on the skin *DO NOT* re-apply the condom until the sore heals completely.

In case urine bags are not available locally, even a foot-ball bladder can be used to collect the urine. The bladder can be attached to the leg in a cloth bag.

1. The bladder should be boiled after washing thoroughly with soap and water and then dried – everyday.



Foot-ball bladder used as urine collecting bag

Cloth bag holder for bladder to be attached to the leg or thigh

Football bladder with stop cock attached to the lower end for easy emptying

IMPORTANT PRECAUTIONS FOR CONDOM USE:

- Be sure it is **not too tight** – it could stop blood flow and severely harm the penis. Avoid non-stretch tape.
- If the penis has erections (gets hard and bigger), try to put on the condom when it is big.
- Remove the condom once a day and wash the penis well with soap and water.
- If possible, remove it at night. Use a bottle or urinal to catch the urine.
- Check the condom and penis often to be sure everything is all right.
- If the penis becomes injured, swollen, or looks sore, remove the condom until the penis is healthy.

> *NOTE:* THE CHILD WITH A SPASTIC [AUTOMATIC] BLADDER MAY NEED DRUGS LIKE PROBANTHINE TO PREVENT KIDNEY DAMAGE. CONSULT A COMPETENT HEALTH WORKER.

Methods for the limp bladder

If the person's bladder is limp (flaccid), it never empties by reflex. The bladder will constantly have urine sitting in it unless an effective emptying method is used.

Boys:

1. Put in a regular catheter every 4 to 6 hours to empty the bladder. Between catheter use, the boy can put on a condom to catch any leaking urine, as described on page 245.
2. A Foley catheter can be used, but may lead to problems (see p. 244).
3. Other alternatives include a surgical operation, which allows the urine to come out through a small opening on the belly into a bag. Or a special catheter is put into the bladder through a small hole in the lower belly. (See also chapter 22, section on bladder and bowel management).

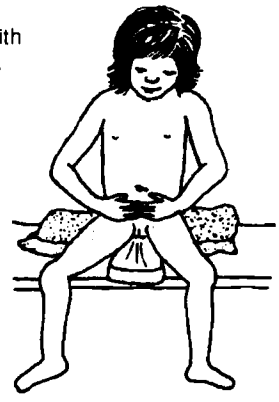
Girls:

1. Try an 'intermittent' (in and out) program, using a regular catheter every 4-6 hours. If there is leaking in between catheter times, use diapers, rags, or a thick clean sanitary pad to catch the urine. Change them often and wash often to protect the skin and prevent sores. If this does not work then try the second method mentioned below.
2. They can use a Foley catheter. This is often the simplest method, but can lead to urinary infections.
3. The surgical procedures mentioned for boys can also be done in girls.

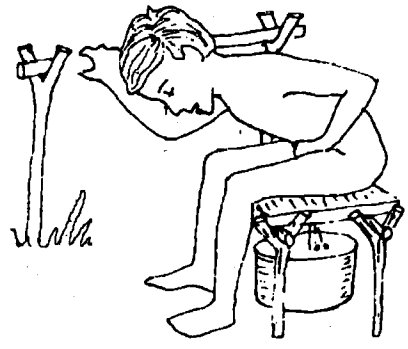
OTHER SUGGESTIONS FOR THE LIMP BLADDER–BOTH SEXES

- The **push method:**

Push down over the bladder with the hands.



Or strain to push urine out by tightening the stomach muscles.



Or put a fist over the lower belly and gently press it by bending forward.

This method is recommended by many professionals, but it can cause problems. If the muscles do not relax to let the urine out, pushing on the bladder can force urine back into the kidneys – causing kidney infection and damage. Therefore, **the push method should only be used if the urine comes out easily with gentle pressure – or if there is no other way possible.**

- With boys with a limp bladder, the condom method can be used. But it is best to also use a regular catheter at least 3 times a day. This is because the bladder does not empty completely, which makes infection more likely.

URINARY INFECTIONS

Persons with **spinal cord injury** or **spina bifida** have a high risk of urinary (bladder) infections, for the reasons we have discussed. Long-term or untreated infections and kidney problems are a common cause of early death. Preventive measures are essential but even when precautions are taken, some urinary infections are still likely to happen. Therefore, it is very important to recognize the signs and provide effective treatment.

Signs

When a person who has normal feeling has a urine infection, it burns when he urinates. The person with spinal cord damage may not feel this burning and therefore has to use other signs to know when he has an infection. He may learn to recognize certain unpleasant feelings, or may only know that he does not feel as healthy as usual. Parents and health workers should learn to listen to the child and be aware of changes in behavior or other things that might mean that he has an infection.

Possible urinary signs

- cloudy urine, possibly with pieces of mucus, pus, or blood specks
- dark or red urine
- strong or bad smelling urine
- increased bladder spasms (cramps)
- increased wetting or changes in bladder function
- pain in the mid-back (kidneys) or side (urine tubes)

Possible other signs

- body aches
- general discomfort
- increased muscle spasms
- fever
- dysreflexia (headache, goosebumps when sweating, high blood pressure, see p. 187.)

Treatment

At the first signs of infection, **drink even more water than usual** and if on intermittent catheterisation, increase the frequency of catheterisation correspondingly. *Antibiotics* (medicines that fight bacteria) may also be necessary. But avoid frequent use of antibiotics because they may become less effective (bacteria may become resistant).

If a person has had urinary infections before, he can start with the last medicine that was effective. If not...

- Start with one of the medicines in **Group 1 on the next page.** If after 2 days the person is still getting worse, try another medicine in Group 1.
- If that does not help, go on to Group 2.
- If none of the medicines of Group 2 help, take the person to a medical laboratory for a 'culture' and 'sensitivity test' of the urine, whereby the urine is examined for the bacteria present in it and what medicine is effective against them.
- If that is not possible, try a medicine in Group 3. If possible, consult a specialist in urinary problems.

If a medicine seems to help, continue taking it for at least a week, or for 4 days after the last signs have disappeared. Do not change from one medicine to another unless the medicine is not working or causes serious side effects.

CAUTION: Many of these medicines sometimes cause serious side effects. Find out about their risks and precautions before using them.

The medicines marked with a star (*) can cause kidney damage unless the person drinks **lots of water.** Even then damage may occur.

Be sure to give the medication in the correct dosage.

TREATMENT FOR URINARY INFECTIONS

		Medical name (and common brand)	Age	Dose	Repeat the dose
Group 1	A.*	Sulfisoxazole (***Gantrisine***)	up to 5 years 5 to 10 years over 10 years	500 mg. 750 mg. 1000 mg.	4 times a day
	B.	Nitrofurantoin (***Furadantin, Macrodantin***)	up to 8 years over 8 years	25 mg. 50 mg.	4 times a day
Group 2	A.	Ampicillin (many brands)	up to 4 years 4 to 8 years over 8 years	125 mg. 250 mg. 500 mg.	4 times a day
		Caution: Do not use for persons allergic to penicillin			
	B.*	Sulfamethoxazole 400 mg. with Trimethroprim 80 mg. (***Bactrim or Septra***)	up to 4 years 4 to 9 years 9 to 12 years over 12 years	1/2 tablet 1 tablet 1-1/2 tablet 2 tablet	2 times a day
		Note: This medicine also comes in double strength (Bactrim DS and Septran DS). Adjust doses if using double strength.			
	C.	Cephalexin (***Keflex***) or a similar Cephalosporin	up to 5 years over 5 years	125 mg. 250 mg.	4 times a day
Group 3	A.	Norfloxacin (400 mg.)	6 to 10 years over 10 years	1/2 tablet 1 tablet	2 times a day
		Note: Take 1 hour before or 2 hours after eating.			
	B.	Tetracyline (many brands) (382 mg.)	over 8 years	500 mg.	4 times a day
		Caution: Do not give to children under 8 years, or to women who are pregnant or breast feeding. If possible, avoid taking milk products with tetracycline.			
All persons with a urinary infection should always drink lots of water while they are taking medicine. After the infection is gone, continue drinking lots of water, and take all preventive measures. Also get regular blood examination done.					

PREVENTION OF URINARY INFECTIONS

- Drink lots of liquid – adults, at least 2 liters (8 glasses) a day.
- Eat apples, grapes, or gooseberries – or drink their juices- or take vitamin C tablets to make urine more acid. Bacteria grow with more difficulty in acid urine. (***Note:*** Orange or lemon juice and other citrus fruits and juices do not work! They make the urine *less* acid.)
- Keep hands, catheter, and collection bags very clean before, during, and after your bladder program.
- Do not lie in bed all day. Stay active.
- Do not clamp the Foley catheter or plug it with anything- unless absolutely necessary – then use a sterile plug.
- Stick to your bladder program. Do not allow urine to sit in bladder.
- Do not let the catheter get bent or twisted so that urine cannot come out.
- If using a standard catheter periodically, be sure to put it in regularly, at least every 4 to 6 hours. To prevent infections, frequency of catheter use is even more important than cleanliness. It is safer to put in the catherter without boiling it, than not to put in. If infections are common, catheterize more often.



To prevent urinary infections, drink LOTS OF WATER

BOWEL MANAGEMENT IN SPINAL CORD INJURY AND SPINA BIFIDA

When there is damage to the spinal cord, almost always a person loses control over when he will have a bowel movement (pass stool). This makes it hard to stay clean, which can be inconvenient or embarrassing. Although he can never get back complete control over the muscles that hold in or push out the stool, **a person can learn to help the stool come out, with assistance, at certain times of day.** This kind of **'bowel program'** can greatly increase the person's self-confidence and freedom for school, work, and social activities.

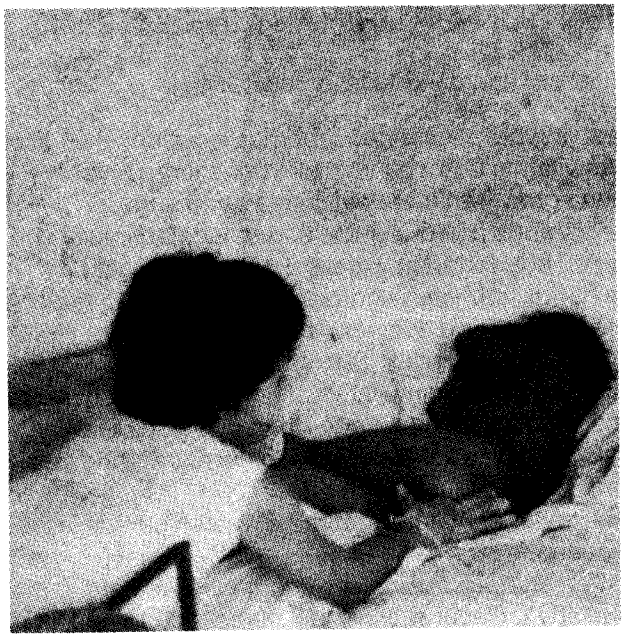
Persons with spinal cord damage also often have problems with constipation, or the formation of hard stools that may wait days before coming out. Some constipation can be an advantage when a person lacks bowel control. But sometimes it can lead to serious problems, such as impaction (see p. 252) or dysreflexia (see p. 218). It is therefore important to **prevent serious constipation:**

- Drink lots of water
- Eat foods high in fiber (such as bran, whole grain cereals, beans, nuts, lotus stem).
- Stick to a scheduled bowel program.
- Keep active.

Planning a bowel program

Any bowel program will work better if you:

- Do the program **every day** (or every other day) and **at the same hour.** Do it even if the person has had an accidental bowel movement shortly before, or has diarrhea.
- Do the bowel program at the same time of day that the person usually had bowel movements before his injury. Often the bowels move best after a meal or a hot drink.
- If possible, do the program on a toilet or pot. The bowels work better sitting than lying.
- Be patient. The bowels sometimes take days or weeks to change their pattern.



An 8-year-old paraplegic girl, Vania, helps a 5-year-old paraplegic girl with her daily bowel program. (See Story of Jesica on p. 225.)

Types of bowel

Different persons require different types of bowel programs, depending on whether their bowels are 'automatic', 'limp', or 'pull back'.

- **Automatic bowel** usually occurs in persons who have muscle spasms in their legs, and an 'automatic bladder'. The muscle or 'sphincter' in the anus stays shut until there is a stimulation in the bowel to make it open, so that the stool can come out. An automatic bowel will 'move' in response to a suppository or stimulation by a finger.

- **Limp or 'flaccid' bowel** usually occurs in persons with low spinal cord damage who have limp (not spastic) legs and bladder. The sphincter muscle in the anus is also limp. So the person tends to 'ooze' or 'dribble' shit. A limp bowel does not respond to finger stimulation.

- **A bowel that pulls back** is neither automatic nor limp. When you put a finger up the anus, you can feel the stool move back up instead of coming out.

PROGRAM FOR AN AUTOMATIC BOWEL

- Start with a suppository if available. With a finger covered with a glove or plastic bag, and then oil or soap, push the suppository about 2 cm. (1 in.) up the anus. Do not push it into the stool, but push it against the wall of the bowel. (Or try the program without a suppository; usually finger stimulation is enough.)

SUPPLIES NEEDED

- non-sterile glove, finger glove, or plastic bag
- lubricant (vegetable or mineral oil works well)
- old paper or newspaper
- soap and water
- if available, ***suppositories*** such as ***Dulcolax*** or glycerine. These are bullet-shaped pills that are pushed into the anus. They stimulate the bowel and cause it to push out the stool.



- Wait 5 or 10 minutes. Then help the person sit on a toilet or pot. If he cannot sit, have him lie on his left side (on top of old paper).

- Put an oiled finger into the anus about 2 cm. Gently move the finger in circles for about 1 minute, until the anus relaxes and the stool pushes out.

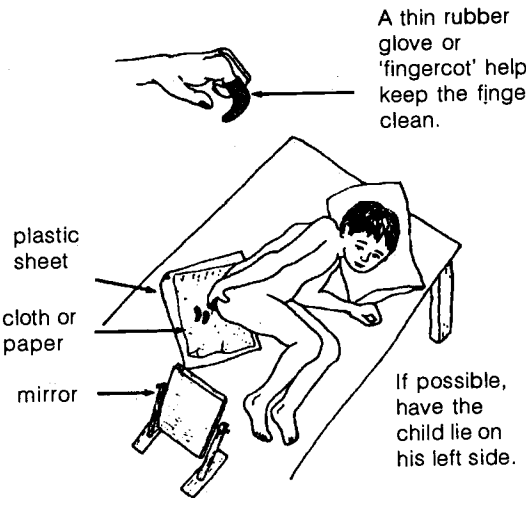
- Repeat the finger action 3 or 4 times, or until no more stool is felt.

- Clean the bottom and anus well and wash your hands.

PROGRAM FOR A LIMP BOWEL

Since the bowel does not push, the stool must be taken out with a finger. It is best done after each meal, or at least once a day.

- If possible, do it sitting on a toilet or pot, or lying on your left side.
- With a gloved and oiled finger, remove as much stool as you can.
- Since a limp bowel tends to ooze stool, eat foods that make the stool firm or slightly constipated (not much stool-loosening foods).



Children can learn to do their own 'bowel program' (See p. 250.)

PROGRAM FOR A BOWEL THAT PULLS BACK

For this kind of bowel, the bowel programs already described usually do not work. Finger stimulation makes the bowel act in the opposite direction, and pull the stool back in. The person will have 'accidents' during the day. Often it works better to,

- First, put some anesthetic jelly (such as *Xylocaine*) up the anus. If you cannot get the jelly, you can mix some liquid injectable *Xylocaine* (lidocaine) with *Vaseline* or any other jelly.
- Wait for several minutes. Then do the automatic bowel program.

OTHER IMPORTANT POINTS

- Do not use enemas or strong laxatives regularly. They stretch the bowel, injure its muscles, and make following a regular program more difficult. A mild laxative like Isabgol may be taken occasionally, when needed. However, **drinking more liquid** and eating food high in fiber is usually enough.
- If there is bright red blood in the stool, probably a blood vessel was torn during the program. Be more gentle! Ensure that finger nails are well cut and smooth. If there is dark, old blood and the stools are black and tar-like, seek medical advice.
- A small amount of liquid stool (diarrhea) may be a sign of 'impaction' (a ball of hard stool stuck in the gut). Only liquid can leak around it. Do not give medicine to stop diarrhea; this could make the impaction worse. Try to get it out with a finger.

Note: It is very important to follow up the kidneys and bladder as well as the anal canal throughout the child's life. Complications which produce symptoms should be dealt with promptly. In the absence of symptomatic complications, the child should have a regular annual check up including simple tests to ensure his kidneys are not getting silently destroyed. This can done be usually in a hospital where the serum creatinine (a type of blood test) and ultrasound examination (an imaging technique where sound waves draw an image of these organs) of the kidney is possible. Whenever necessary, a urine culture may also need to be done

CHAPTER **26**

Leprosy

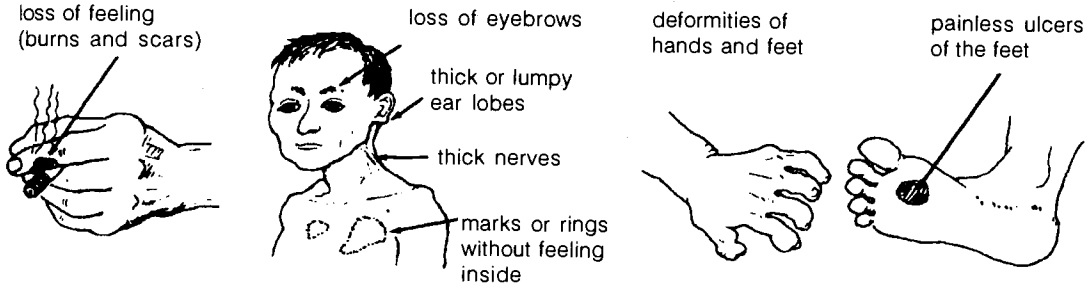
Hansen's Disease

India has approximately 4 million people with leprosy – the largest number in South East Asia. One out of every third person with leprosy in the world is an Indian. Tamil Nadu has the largest number of people suffering from leprosy.

- The areas of high prevalence are now found mainly in the South-Eastern part of the country which includes the States of Tamil Nadu, Orissa, Bihar, Pondicherry and Andaman and Nicobar Islands.
- The areas of moderate prevalence are found mostly in the Central and South-western part, the Eastern part of the country and the Himalayan foot hills. The areas of low prevalence are found mainly in the North-Western parts of the country.
- Out of the 4 million cases in India, 15 to 20 per cent belong to the Multi-bacillary group which are infective and the balance are pauci-bacillary (least infective). 20 to 25 per cent of the cases are among children. The prevalence of leprosy among boys and girls is more or less the same. However, in adults, the prevalence is nearly 2 times in males than in females. The percentage of the deformity among prevalent cases is nearly 6-12 percent (1981).
- Out of 450 districts in India, 201 are high endemic for leprosy with a prevalence of 5 or more per 1000 population. Another 7 districts have prevalence varying between 2 and 5. The remaining 172 districts have prevalence below 2,000. These districts are distributed among 32 States and Union Territories.

Ancient Chinese scriptures as well as the Bible mention leprosy. Indian Vedic writings as far back as 400 B.C. refer to Leprosy as **'KUSHTHA'**. The term is used even today in India. The **'Sushruta Samhita'**, a book on surgery written in 600 B.C., gives a description of the disease and its treatment.

What is leprosy? It is an infectious disease that develops very slowly. It is caused by germs (bacilli) that affect mostly the skin and nerves. It can cause a variety of skin problems, loss of feeling, and paralysis of and paralysis of some of the muscles.



How do people get leprosy? It can spread only from some persons who have untreated leprosy, and only to other persons who have 'low resistance'to the disease. It is probably spread either through sneezing or coughing, or through skin contact. A very large majority of persons persons
who come into contact with leprosy have a natural ability to resist it. Either they do not get it at all, or they get a small unnoticeable infection that soon goes away completely.

From the time a person is first infected with leprosy germs, it often takes 3 or 4 years for the first signs of the disease to appear.

Leprosy is not caused by evil spirits, by doing something bad, by eating certain foods, or by bathing in river water, as some people believe. It is not hereditary and children of mothers with leprosy are not born with it. However, **children who live in close contact with someone who has untreated leprosy are more likely to get it.** This is because they are more exposed to the germs coughed out or sneezed out by the patient, especially in the close confines of their home.

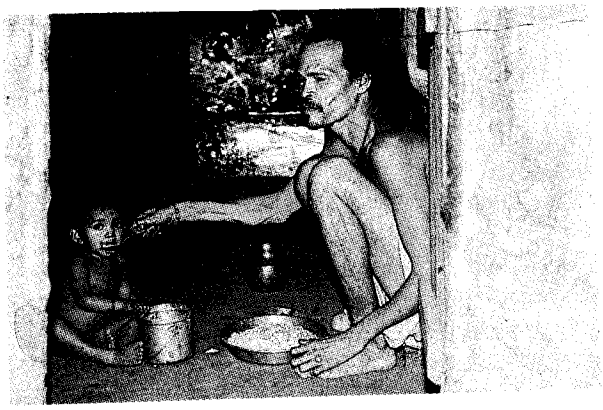
How common is leprosy? Leprosy is much more common in some parts of the world than others. It is more common where there are crowded living conditions and poor hygiene. But rich people can also get it.

Even with improved methods for treatment, today there may be more persons with leprosy than even before. More than 12 million people have leprosy. In some villages in Asia,Africa, and Central America, 1 person in 20 has leprosy.

Can leprosy be cured? Yes. There are medicines that kill leprosy germs. Usually within a few days of beginning treatment, a person can no longer spread the disease to others. (In fact, most persons, by the time their leprosy is first diagnosed, can no longer spread it). However, **treatment in some persons must be continued for some months to prevent the disease from coming back.**

Is early treatment important? Yes, early treatment stops the spread of leprosy to others. Also, if treatment starts before loss of feeling, paralysis and deformities have appeared, recovery is usually complete and the person is not physically or socially disabled.

Persons receiving regular,effective treatment do not spread leprosy.



Checking children for signs of leprosy

In areas where leprosy is common, health and *rehabilitation* workers should work together with parents and schoolteachers to **check all children regularly for early signs of leprosy.** Most important are regular checkups of children in homes where persons are known to have leprosy. Checkups should be done every 6 to 12 months and should be continued for at least 3 years. Children in the age group of 10 to 15 years are more susceptible.

EARLY SIGNS

A slowly growing patch on the skin that does not itch or hurt. The patch may be somewhat different in color from the surrounding skin.(Patches of leprosy are never completely white, and are not scaly, except during a reaction – see p.258).

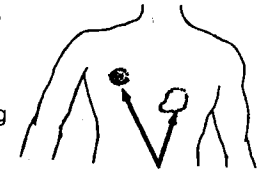
Note: In early skin patches, feeling is often normal, or nearly so. **If feeling is clearly reduced inside a patch, leprosy is almost certain.**

WHAT TO LOOK FOR

Examine the whole body for **skin patches,** especially the face, arms,back, butt, and legs



If you find a slightly pale patch without a clear edge, keep watching the spot. Unless feeling is reduced inside the patch, look for other signs before deciding it is leprosy.(Many children have similar pale spots on cheeks and arms that are not leprosy)



ringworm like patches, with or without raised border

LATER SIGNS

1. Tingling, numbness, or some loss of feeling in the hands and feet.

   Or definite loss of feeling in skin patches.

TEST INSIDE THE SKIN PATCHES FOR REDUCED FEELING

When the tip of a feather or stiff thread, lightly touch the skin inside and outside the patch and have the child tell you (without looking) where he feels the touch.



In a similar way, test for a numbness or reduced feeling in the hands and feet.



thread tied to stick

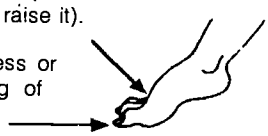
If the child cannot feel the thread, try pricking lightly with a sterile needle.

WARNING Sterilize the needle in a flame before testing another child.

2. **Slight weakness or deformity in the hands and feet.**

   drop foot (Child cannot raise it).

   weakness or bending of toes



Have the child straighten her fingers. If she cannot do this, it may be a sign of paralysis from leprosy.



Also have the child try to touch the base of her little finger with her thumb



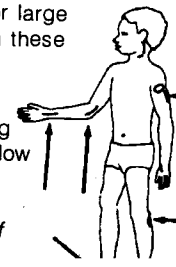
Muscle weakness here makes this movement difficult and may be a sign.

(***CAUTION***; These weaknesses may also be caused by polio, muscular dystrophy, or other problems).

3. **Enlargement of certain nerves,** with or without pain or tenderness. The affected nerve feels like a thick cord under the skin. When they are quite thick, they may be easily seen.



Check for large nerves in these places



thickening nerve below the ear (From *A Manual of Leprosy*

Also check for large nerves in or near skin patches

Diagnosing leprosy

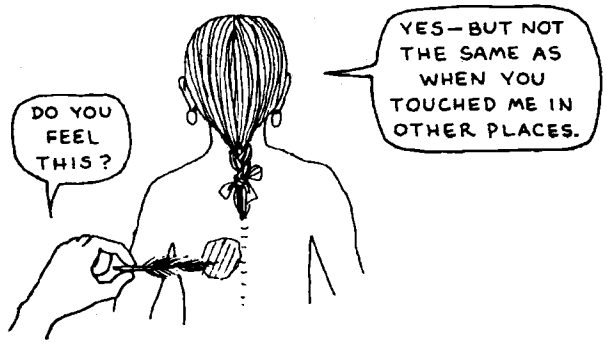
Although skin patches are often the first sign of leprosy, many other diseases can cause similar patches. Only when there is a loss of feeling inside the skin patch, as compared with the skin outside the patch, can we be almost sure the person has leprosy. However, in some forms of leprosy, loss of feeling in skin patches may develop only years later, or not at all. Therefore, other evidence of leprosy must be looked for.

Another sign of leprosy – tingling, numbness, or loss of feeling in hands and feet – may also have other causes.

To make a fairly certain diagnosis of leprosy, the person should have at least 1 of these 3 major signs:

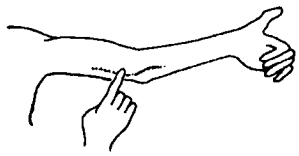
1. **definite loss or change of feeling in skin patches**

   Note: Leprosy patches on face often do not lose feeling as much as on other parts of the body.



2. **definite enlargement of nerves**

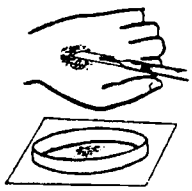
   (For nerves to check, see p.255)



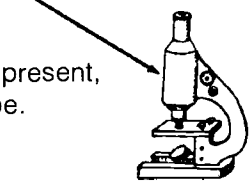
3. **presence of leprosy bacilli in a 'skin smear'**

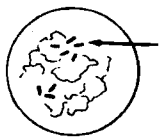
   A 'slit skin smear' is prepared by making a small slit in the skin of an affected part, and removing some tissues or patch fluid from there, for examination. The sample is placed on a glass slide, colored with special stains, and examined with a microscope.

   The bacteria(bacilli) of leprosy, if present, can be seen under the microscope.



taking a 'slit skin smear' from a skin patch





leprosy bacilli as seen in the microscope.

Whenever you suspect leprosy but the diagnosis is uncertain, a 'skin smear' should be taken (by a trained worker).

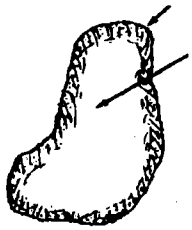
Note: Not many persons with leprosy show all 3 of these signs. Persons with loss of feeling in skin patches usually have no bacilli in their skin smears.

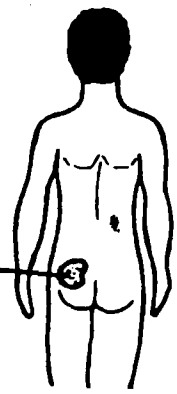
Types of leprosy

Depending on how much natural resistance a person has, leprosy appears in different types. Here are the characteristics of the main types.

TUBERCULOID LEPROSY (TT)
Non- infectious extreme

- in persons with relatively high resistance
- no bacilli in skin smear
- Person cannot pass leprosy on to others.
- Skin patches are few. They may be very variable in appearance, but often have raised margins and

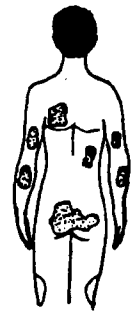




- Feeling is usually reduced or absent in centers of the skin patches.
- Skin patches usually lose hair and are dry(do not sweat).
- Skin on the face is not usually thickened.
- Nerve damage appears early, but usually only involves loss of feeling in skin patches. Usually it does not affect the eyes, hands, or feet. If it does it often happens early and causes loss of feeling or strength in only one hand or foot.
- Usually responds quickly to treatment because the body helps fight the disease.

'BORDERLINE' LEPROSY
combines features of both tuberculoid and lepromatous leprosy.

- few to many bacilli in skin smears.
- many skin patches, raised or flat with well-marked, often irregular edges, and some feeling loss; patches about the same on both sides of the body.



- Borderline leprosy may suddenly shift toward one or the other extreme. When these shifts occur, 'leprosy reactions' are especially likely to appear(see p.258).
- Severe nerve damage often results, with loss of feeling and loss of strength in both hands and both feet, with deformities.



Depending on where it falls along the line between the two extremes, borderline leprosy is divided into:

borderline tuberculoid(BT)

borderline (BB), and

borderline lepromatous(BL)

LEPROMATOUS LEPROSY (LL)
Infectious extreme

- in persons with very low resistance
- bacilli – very many in skin smears
- Person can pass leprosy to others(until treated),
- There are usually very many skin patches – variable in appearance, but often with raised lumps or thickened areas. In early stages, feeling is usually normal inside these patches.



- The skin of the face may become thick, lumpy, reddish, especially over the eyebrows, cheeks,nose and ears.



THE 'LION FACE' OF LEPROMATOUS LEPROSY

- The bridge of the nose may gradually sink in.
- Nerve damage and paralysis often appear late, if the leprosy is not treated.
- Loss of feeling and strength affects both hands and both feet equally.
- Response to treatment is often slow. Treatment must usually be continued for at least 2 years.

Leprosy reactions

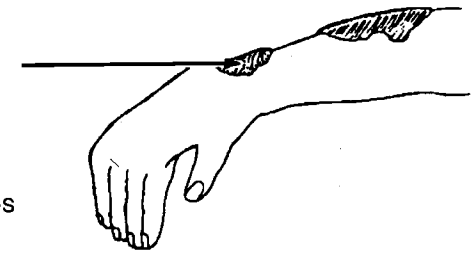
These may be something like an allergic reaction to the leprosy bacilli. Leprosy reactions can happen in untreated persons, during treatment, or after treatment has stopped. Reactions can occur when there are changes in the body, such as puberty in boys, in late pregnancy or following childbirth, during illness from other causes, after vaccination, or at times of emotional stress.

There are 2 types of leprosy reactions:

Type 1 reactions happen in persons with borderline leprosy when the body increases its fight against the leprosy germs. There is danger of new weakness and loss of feeling.

Signs to watch for are:

- skin patches may become swollen and red.
- swollen hands and feet
- new tingling or weakness of hands and feet
- pain or discomfort along nerves(Rarely, lumps along the nerves form sores and drain pus).



IMPORTANT: Reactions sometimes cause new weakness and loss of feeling **without nerve pain.**

Type 2 reactions happen with lepromatous leprosy. The body is reacting against too many bacilli.

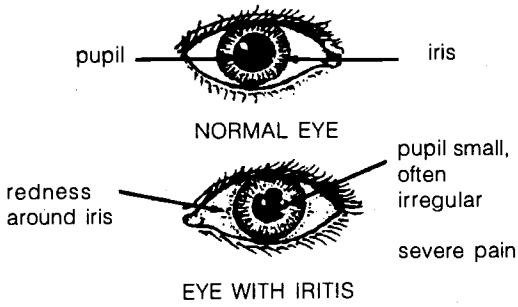
Signs may include:

- swollen, reddish, or dark lumps under the skin, especially on the face, arms and legs.
- fever
- pain in testicles, breast or fingers
- stuffiness or bleeding of the nose
- red eye, with or without pain.

Danger This may lead to **iritis** or loss of vision unless treated early.

Rarely, this reaction causes death due to swelling of the mouth, throat or lungs, or to kidney problems.

IRITIS (INFLAMMATION OF THE IRIS)



Pain may begin suddenly or gradually. The eye waters a lot. It hurts more in bright light. There is no pus as with conjunctivitis. Vision is usually blurred. **This is a medical emergency.** Antibiotic ointments do not help. **Get medical help.**

If untreated, leprosy reactions can quickly lead to permanent nerve damage with increased paralysis of the hands, feet or eye muscles, or to permanent damage to the eyes.

Early treatment of leprosy reactions is very important to prevent paralysis, deformity, and blindness.

Treatment of leprosy reaction is discussed on p.261.

TREATMENT AND MANAGEMENT OF LEPROSY

Treatment and management of leprosy include 4 areas.

1. **Long-term medical treatment** to control the leprosy infection should begin as early as possible.

2. **Emergency treatment** when necessary to control and **prevent further damage from leprosy reactions.**

3. Safety measures, aids, exercises and education to **prevent deformities** (sores, burns, injuries, contractures).

4. **Social rehabilitation**: Work with the individual, the parents, the schools, and the community to create a better understanding of leprosy, to lessen people's fears, and to increase acceptance, so that the child or adult with leprosy can lead a full, happy, meaningful life.

Medical treatment

Medical treatment of leprosy varies according to the policies and resources of the particular country and health ministry. For years,**DDS (dapsone)** has been the main drug used. Unfortunately, in some areas, the leprosy bacilli are becoming 'resistant' to DDS(are not harmed by it).

Rifampin usually works much faster against leprosy. However, it is more costly and can also cause serious side effects. Still, where possible, it should be used. To prevent development of resistance, it is usually given in combination with other anti – leprosy medicines. When given in combination wtih DDS, rifampin probably needs to be given only once a month. This reduces both cost and side effetcs.

Clofazimine, although less effective in killing leprosy bacilli than rifampin, has the advantage that it also helps control leprosy reaction.

Multi-drug treatment, consisting of rifampin, DDS and clofazimine, is now recommended by the World Health Organization. It greatly reduces the time needed for treatment, especially for tuberculoid leprosy.

Instruction for the dosage and precautions for these different medicines should be obtained from the local centre of the National Leprosy Control Program. Usually it is wise to cooperate with these programs instead of trying to treat leprosy by yourself because these drugs have side effects.

Adverse side effects:

- **Dapsone:**

  They may include:-

  anaemia
  allergic rashes – including exfoliative dermatitis
  jaundice
  fixed drug eruption

NOTE: **Adverse side effects are uncommon when dapsone is used in the recommended daily doses.**

- **Rifampicin:**

  Reddish discoloration of urine.

  nausea – vomiting
  urticarial rashes
  flu syndrome
  purpura
  jaundice
  haemolytic anaemia
  shock – renal failure

  Toxic syndromes may be encountered depending upon the dosage and the intervals between doses. It should be avoided during the first trimester of pregnancy.

- **Clofazimine:**

  Reversible, dose-related, brownish black generalized discoloration of the skin, ichthyosis GI Tract: nausea, vomiting, abdominal pain, diarrhea, anorexia and weight loss.
  Eyes: Conjunctival dryness.

Wherever complications cannot be managed by the PHC Medical Officer, the patient should be referred to the District level authorities.

Importance of long-term treatment'

Treatment to cure leprosy takes a long time: from 1 to 2 years or more, depending on the type of leprosy and the medicine used. If treatment is stopped too soon,not only can leprosy return, but sometimes a leprosy reaction may result which can cause even more nerve damage and paralysis or blindness.

It is therefore **essential that health and rehabilitation workers make sure that the person with leprosy and her family understand the importance of taking the medicines regularly**

Health centers should take care always to keep a reserve supply of medicines on hand.

TREATED EARLY, LEPROSY NEED NOT BE A DEFORMING OR DISABLING DISEASE

Treatment of leprosy reactions

As we mentioned on p.253, feeling loss, paralysis, and deformities need not happen to a person with leprosy. **Early diagnosis and treatment together with quick care of leprosy reactions should prevent the development of many deformities**

Care of a leprosy reaction has 4 objectives:

- Prevent nerve damage that causes loss of feeling, paralysis and contractures.
- Stop eye damage and prevent blindness.
- Control pain.
- Continue with medicine to kill leprosy, bacilli and prevent the disease from getting worse.

Care includes:

1. **Medicine to reduce pain and inflammation**

   For mild reactions (skin inflammation but not pain or tenderness of nerves) **aspirin** is the best and cheapest drug. For dosage and precautions, see p.154.

   Chloroquine (a medicine for malaria) is also effective. To adults, give 2 tablets at night (to avoid dizziness) for no more than 2 or 3 weeks. Give less to children, according to their weight.

   For severe reactions (pain along nerves, increasing tingling, numbness or weakness, eye irritation, or painful testicles) **corticosteroids** (prednisolone) may be needed. Because this is a medical emergency and because **corticosteroids are dangerous and often misused medicines,** if at all possible **get experienced medical advice before using them**

2. **Anti-leprosy medicine should be continued throughout the leprosy reaction.**

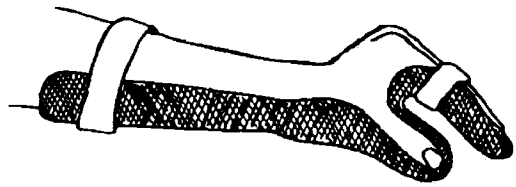
   Clofazimine can be used instead of DDS, as **clofazimine helps to reduce reactions and fights the leprosy bacilli.** The dose of clofazimine can often be increased(to 200 mg. daily in adults) and later reduced as the reaction lessens.However, for severe reactions that damage nerves, prednisolone is needed.

Under the National Leprosy Eradication Program, all anti leprosy medicines are given free of cost.

3. Splinting and exercise

Holding the affected limbs in splints during a severe reaction helps reduce pain and prevent nerve damage and contractures(See Chapter 8).

Joints should be splinted in the most useful position. Splints can be made of plaster bandage or molded plastic(see p.660). Very carefully pad splints for hands or feet that do not feel pain.



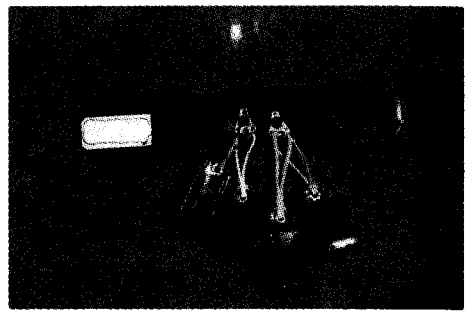
A good splint for the hand – to avoid contractures and maintain a useful position.

Leave the splint on day and night until pain and inflammation are gone. Remove only for gentle range-of-motion exercise at least once a day(See Chapter 43)

Surgery can be avoided if splints are used before severe deformities set in. Here is an example.



Young boy with right hand deformity (a claw hand)



Wrist belt with finger loops can correct early deformity without surgery.



He was fitted with a wrist belt with finger loops to strengthen the intrinsic muscle (muscles that help the movement of the fingers)power.



After two months of splinting his fingers straigthened.

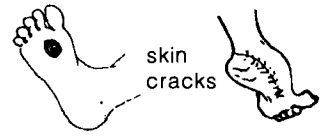
Wrist belt with finger loops.

The belt is wrapped around the wrist and the loops for each finger are attached to the hook by rubber bands.

- This prevents the hyper – extension and contracture of the fingers.
- Strengthens the intrinsic muscles of the hand and extensor backward bending of fingers.
- Corrects the hooding deformity of the fingers.
- Provides functional ability,specially for motor activity.
- Assists the transfer tendon after reconstructive surgery of the hand.

Cause of deformities

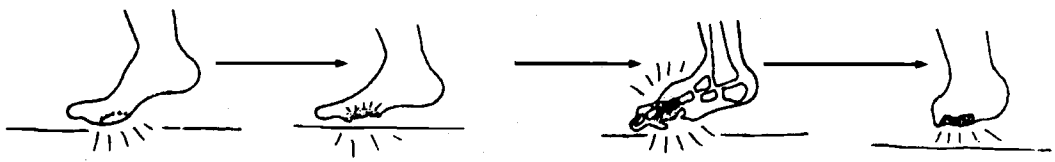
When most people think of leprosy, they think of the severe deformities of the advanced case: deep open sores (ulcers), clawed fingers, gradual loss of fingers and toes, and eye damage leading to blindness. Actually, these deformities are not caused directly by leprosy germs, but result from damaged nerves. Nerve damage causes 3 levels of problems, one leading to the next:

LEVEL 1: loss of feeling, of sweating, and of strength in certain muscles.	LEVEL 2 : injuries, joint stiffness	LEVEL 3: progressive deep infections with bone destruction and loss of vision.
Eyes do not blink normally  leads to	eye irritation and infection  leads to	scaring and blindness 
Hands do not feel, skin dry, weakness of fingers and thumb  leads to	stiffness and contractures of fingers and thumbs; also burns and injuries  leads to	loss of bone 
Feet do not feel; skin dry: drop foot  leads to	painless sores and injuries; stiffness and contractures;  skin cracks leads to	loss of bone 
often PREVENTABLE with medical treatment of leprosy **before** there is nerve damage	often PREVENTABLE with protective eye and skin care and exercise to keep full movement of joints.	often PREVENTABLE with careful early treatment of sores, burns, and infections.

When there are level 1 problems, there is a **lifelong danger** of level 2 and 3 problems. Because feeling has been lost, the person no loner protects herself automatically against cuts, sores, thorns and other injuries. And because they do not hurt, these injuries are often neglected.

For example, if a person with normal feeling walks a long way and gets a blister, it hurts, so he stops walking or limps.

But when a person with leprosy gets a blister, it does not hurt.	So he keeps walking until the blister bursts and becomes infected.	Still without pain, the infection gets deeper and attacks the bone.	In time the bone is destroyed and the foot becomes more and more deformed.



Usually, leprosy bacilli cannot be found in these open sores. This is because the sores are not caused by the bacilli. Instead, they are caused by pressure, injury, and secondary infection.

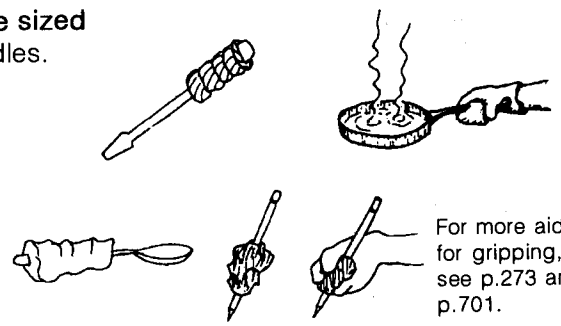
PREVENTION OF INJURY for persons with loss of feeling and strength

Hands: When you work with your hands, or cook meals, take special care. Never pick up a pan or other object that ***might*** be hot without first **protecting your hand with a thick glove or folded cloth.** If possible, avoid work that involves handling sharp or hot objects. **Do not smoke.**

- **Use tools with smooth, thick/large sized handles**, or wrap cloth around handles.

To help the person with weak or deformed fingers hold a tool or utensil, you can mold a handle to the shape of the person's closed hand.

Use epoxy putty, or plaster of Paris mixed with a strong glue. Have the person grip the handle while it is still soft. Then let it harden.



For more aids for gripping, see p.273 and p.701.

Here are a few examples of simple and cheap aids that persons with hand deformities can use.

The material used for making these aids is an epoxyresin called Araldite A.V. 1001 IM (brandname is MODULAN). This medium has been successfully used for moulding the handles of household articles as well as those used in different trades.

The type of grip needed is designed to suit a particular function and the person who will use it. If the person has difficulty in performing that function you can use wires, plastic tubes, rubber belts etc. for improving the grip.

Modulan can also be used for making the molded medial arch support and fixed over the insole of an ordinary MCR foot wear. (medial arch is explained on page 132).

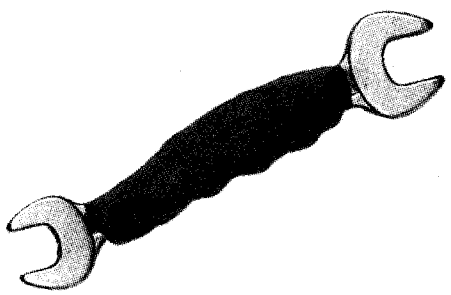


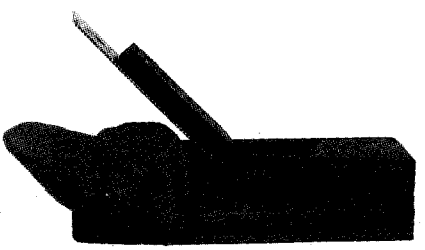
Abnormal grip due to deformed hand.



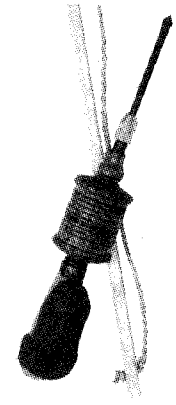
Better function with MODULAN Grip-Aid (the glass is made of stainless steel)

Made to measure modulan grip aids used in various trades.







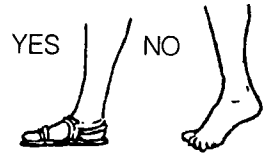


The modulan grip-aid if necessary can be altered by filing and sandpapering. If necessary, the modulan grip aid can be removed from the tool or utensil by a sharp blow with a hammer. Made to measure modular grip aids for people with leprosy.

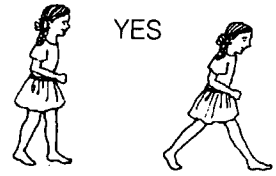
For more information on materials and how to make low cost aids for people with leprosy, contact: Dr. Ganapati, Vidnyan Bhavan, 11 V.N. Purav Marg, Bombay 400 022, Schieffelin Leprosy Research and Training Centre, Karigiri, North Arcot, Dist., Tamil Nadu.

Feet :

- **Avoid going barefoot. Use shoes and sandals.** (For suggestions on appropriate footwear, see the next page).



- **Learn to take short steps.** This helps protect the feet.



Eyes: Much eye damage comes from not blinking enough, because of weakness or loss of feeling. Blinking keeps the eyes wet and clean. If the person does not blink well, or his eyes are red, teach him to:

- Wear sunglasses with side shades, and maybe a sun hat.
- Close the eyes tightly often during the day, especially when dust blows.
- Roll the eyeballs up as you try to close eyes tight.
- Keep eyes clean. Wash well around eyes, keep flies and dirty hands away.





INJURY CARE

Eyes: Close eyes often. If necessary, use a simple eye patch. If eyes gets infected (form pus) use an antibiotic eye ointment. Put the ointment into the lower lid without touching the eye.





Hands and feet: If you have a cut or sore, keep the injured part very clean and at rest until it has healed completely. Take care not to injure the area again.

Things to do everyday



- **Checkups**: At the end of each day(or more often if you work hard or walk far) **examine your hands and feet carefully** – or have someone else examine them. Look for cuts, bruises, or thorns.. Also look for spots or areas on the hands and feet that are red hot, swollen, or show the start of blisters. If you find any of these, rest the hands or feet until the skin is completely normal again.
- If the skin gets dry and cracks, **soak the feet daily**, in water for at least 20 minutes. Then rub cooking oil, *Vaseline*, or lanolin hand cream into them(not butter or animal fat). These attract insects and rats).
- As you rub oil into the hands and feet, do stretching exercises to keep the complete range of motion in the joints.



With continued daily care, most deformities of leprosy can be prevented.

PREVENTION of contractures and deformities in persons with paralysis

Prevention of *contractures* from paralysis due to leprosy is similar to prevention of hand and foot contractures due to polio and other forms of paralysis(See p.91). However, loss of feeling makes prevention more difficult.

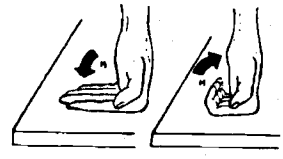
Exercises to maintain full range of motion are covered in Chapter 43 (see especially p.458 to 461).

- Exercises to prevent fixed clawing of the hands can be done by..

. . .gently straightening the fingers like this:



and like this :



Open your fingers as much as you can without help. Then use your other hand to open them the rest of the way. Close fingers and repeat.

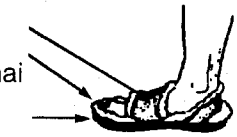


- A good exercise to prevent 'tiptoe' contractures with 'foot drop' is to stretch the heel ***cords*** by leaning forward against a wall or by squatting with heels on the ground.

Footwear for persons without feeling in their feet

The best footwear has:

- a well-fitted upper part that does not rub and has plenty of toe room(or leaves toes open).
- a soft innersole about 1 cm thick.
- a tough under-sole so that thorns, nai and sharp rocks do not injure foot.



- Footwear should be acceptable (not look too strange or unusual) so that the person will use it.
- No nails in the manufacturing process.

AVOID shoes or sandals which cannot be adapted

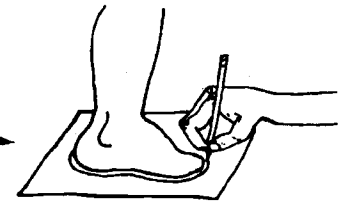
- plastic shoes or sandals
- soft-solded sandals or thongs that thorns can pass through
- using nails to fasten heels and soles (These might poke through and injure the foot. Better to sew on soles or use glue.)

NO



Possible ways to get footwear

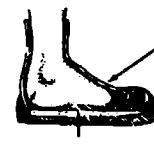
- Contact a leprosy hospital with a footwear workshop. They can make sandals if you send a tracing of the foot.



- Check the market. You may find a canvas shoe or tennis shoe that already has a good insole.



- Or you can put soft insoles into the shoes. ***Caution:*** If you put a thick insole into a standard shoe, there may not be enough room for the toes- unless you cut out the part over the toes and leave them open.

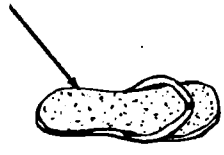


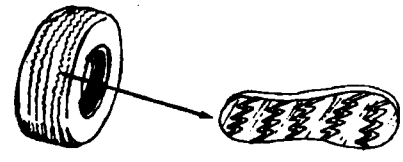
soft insole

An insole that is thick may work if the foot is already short.

- Make(or have a local shoemaker make) special footwear.

For the inner sole, you can use a soft sponge sandal or 'thong'. Or,buy 'microcell' rubber, which is soft but firm.





For the under-sole you can use a piece of old car tyre. (Side wall of the tyre should be used and not the tread surface)

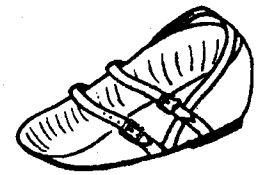


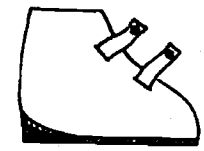
- For persons who have developed sores on their foot here,



a bar here or a foot support here may help take pressure off the ball of the foot and prevent new sores.
This should be done at a leprosy centre.

- A very helpful lining for preventing sores is a soft, heat moldable foam plastic called ***'Plastazote'***. For instructions on making footwear with ***Plastazote***, see ***Insensitive Feet*** on p.770.





- For persons with a **'drop' foot** a brace or 'lift' can help prevent sores and injuries.

You can get a brace or support at a rehabilitation workshop, or make a specially-fitted, well-padded plastic brace(see Chapter 59).



Or make a simple device to hold the foot up.



LEPROSY AND THE COMMUNITY

Historically, there has been a lot of fear and misunderstanding about leprosy. Persons with leprosy have often been thrown out of towns or treated with cruelty. Until recently, governments took persons with leprosy away from their families and locked them up in special institutions or 'leprosaria'. All this added to people's fears.

Today, leprosy can be cured-without any deformities or disabilities if treatment is begun early. It can be treated in the home. The person can continue going to school or to work. Having leprosy need not disable the person physically or socially.

But in many communities fear and misunderstanding remain. Persons still refuse to admit – even to themselves – the early signs of leprosy. particularly in those communities where there are fewer people with leprosy. They delay in getting treatment until permanent deformities appear. The disease continues to be spread to others by those who are not yet treated. And so the myth and the fear of leprosy are kept alive.

To correct this situation will require the efforts of all health and rehabilitation workers, schoolteachers, religious and community leaders, families of persons with leprosy, and organizations of the disabled. These steps are needed:

1. **Information and Education** Schools, health centers, comics, radio and television can be used to help educate the community about leprosy. Information should:
   - try to lessen the fears people have about leprosy and let them know it is curable.
   - stress the importance of early diagnosis and treatment.
   - tell people how to recognize early signs and where to get treated.
   - include popular stories of persons who think they might have leprosy, decide to get help, and are cured.

2. **Integration of leprosy programs** into general health care. Too often leprosy control is done as a separate program. It is important that people (and health workers) begin to see leprosy as 'just another serious health problem'- like diarrhea in children.

3. **Regular screening** (mass checkups) of children for skin patches and other early signs of leprosy. This can be part of a CHILD-to-child' program (see Chapter 48) in which school children learn first to examine each other, and then their younger brothers and sisters. A 'CHILD-to-child Activity Sheet on Leprosy' is available from TALC.



Screening school children for leprosy, India. (Photo, The Leprosy Mission.)

4. **Community pressure** and government orders to let children being treated for leprosy attend school, find work, attend festivals, and take part in public functions. (Organisations of disabled persons can help make this happen).

5. **Community support groups** to help persons with leprosy feel accepted, cared for, and respected; also to make sure that they take their medicines regularly and learn to prevent deformity. Where needed, support groups can help the persons with leprosy get the schooling, health care, work, and social rights they deserve.

The example of a health worker who welcomes persons with leprosy and is not afraid to touch them can do much to calm needless fears and encourage acceptance.

CHAPTER 27

Amputations

An amputation is the loss of some part of the body. Rarely, children are born without one or both hands or feet. More often, children lose one arm or leg because of injuries in accidents. About 80 percent of all amputees live in the villages. Accidents with agricultural implements are a major cause of amputations. Machines, like fodder cutters are often used without proper safety devices. Adults working on these machines and a large number of children while just playing with them get seriously injured, leading to the amputations of fingers and arms (see photo below). Thresher accidents often result in severe injuries of the forearm and even arm, resulting in amputations.

Accidents on railway tracks are another significant cause of amputations. Children of migrant rural families, driven by poverty to live in huts along the railway tracks are exposed to the dangers of moving trains.

Sometimes, **lack of proper care of the wound** can lead to the amputation of a limb. For example, often tourniquets or tight bandages around the limb are applied as a first aid for snakebites and for control of bleeding. As long as they are applied properly for short periods and removed in an hour or so, no damage may occur. However, as often happens, several hours go by before the child can be brought to a hospital or rehabilitation centre. All that can be done then is to amputate the limb. **Tightly applied plaster and splints** can also lead to the blockage of the blood supply to the arms and an unnecessary amputation of the limb (see page 274).

In the urban areas, road accidents are a significant cause of amputations. The people who get disabled or die in these accidents are largely those riding motorcycles and cycles, or those on foot and children living in huts along the roads.

Sometimes limbs must be cut off because of advanced bone infections or dangerous tumors (cancers), burns, leprosy. Surveys around the country have shown that most children and adult amputees are poor people. There are also many more men then women amputees.

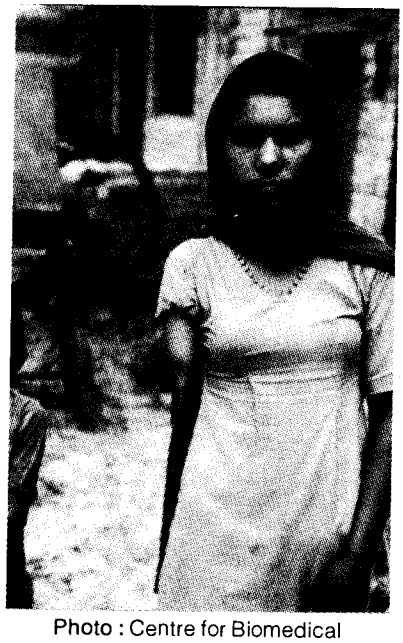


Photo : Centre for Biomedical Engineering I.I.T. Delhi.

Fodder cutters used without proper safty devices have led to injuries and often amputations



Photo : Centre for Biomedical Engineering I.I.T. Delhi.

Deciding what to do for a child with an amputation depends on a number of things, including the age of the child at the time of amputation, the amount of amputation, and above all, what the child (and parents) want and accept.

MISSING BOTH HAND (any age)



He will probably want and accept hooks, or whatever can help her hold things better.



Until he can get gripping hooks, figure out ways to attach tools and utensils to his stumps so he can do more for himself.



A child with high arm amputations from birth often learns to use his feet almost as well as his hands.



MISSING ONE HAND



If she was born that way and is given an artificial limb early, she will usually accept it and keep using it.

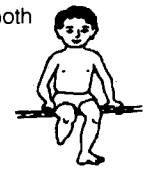


But if her hand was amputated as an older child or she has gone for a long time without an artificial limb...

.....She may prefer to keep using the stump, and refuse a limb even if one is made for her.



AN AMPUTATION BELOW THE KNEE (one or both legs)



He should get an artificial leg as soon after the amputation as possible – or by one year of age.



A growing child will often need a new, larger limb. Therefore, try to fit him with low-cost limbs that are easy to replace.



Limbs with detachable feet – although often expensive-can be lengthened.



ONE LEG AMPUTATED ABOVE THE KNEE



Up to age 10 (or more) she can walk well with a straight leg (no knee joint).



When older, she may prefer and will often walk better on a leg with a knee joint (if the family or program can pay for it and can keep replacing it as the child grows).



BOTH LEGS AMPUTATED ABOVE THE KNEES



When very young, he may move about most easily on short 'stump' limbs.

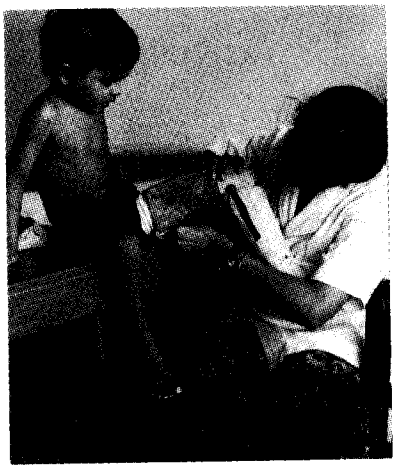


When older, he may prefer longer limbs that make him as tall as other children – even if this means using crutches.



Children with very high amputation of the legs **may do best in wheelchairs.**

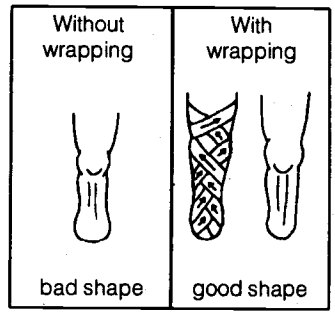




CARE OF THE AMPUTATED LIMB

The goals in caring for the stump are to maintain **a good shape** and **good position** for fitting an artificial limb. This means taking active steps to :

1. **avoid swelling,**
2. **keep the full range of motion** (prevent *contractures*) and,
3. **maintain strength.**

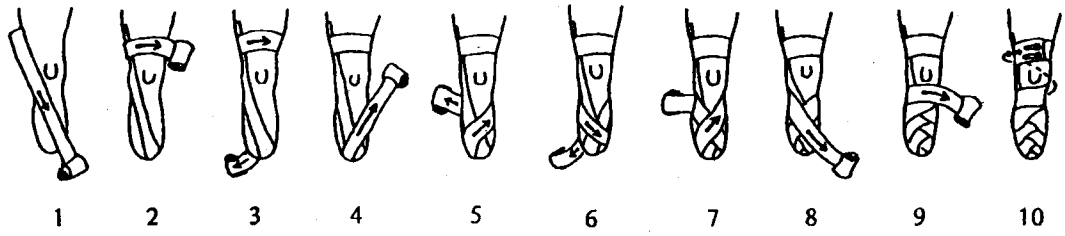


WRAPPING THE STUMP

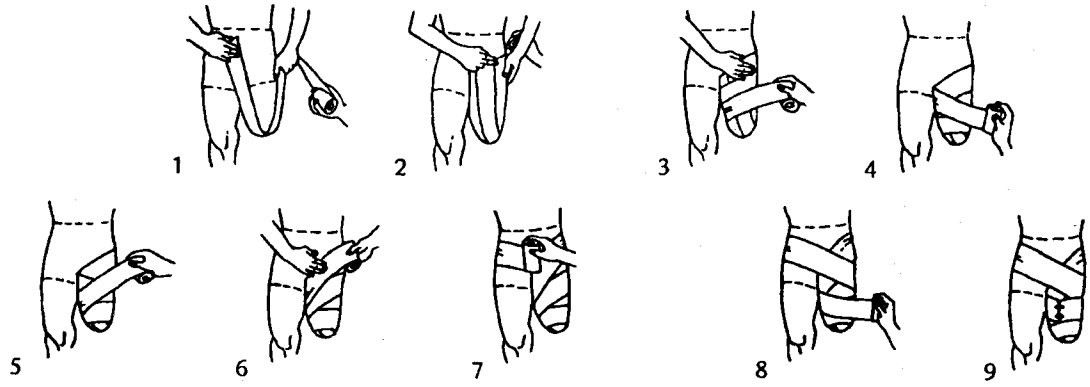
To prevent swelling and keep a good shape for fitting an artificial limb, it is important to wrap the newly amputated limb for a long time after it has been cut off.

The leg should be wrapped in a way that squeezes the liquid in the leg upward (rather than trapping it at the end).

Below knee

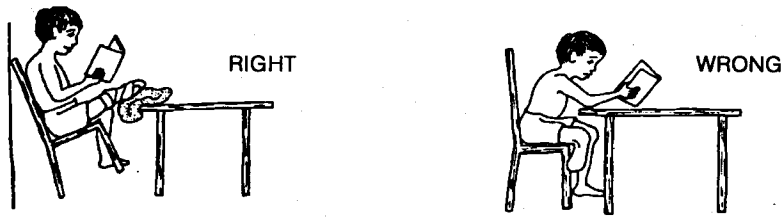


Above knee



ELEVATING THE STUMP

In addition to being wrapped, a newly amputated limb should be kept lifted high up most of the time. Avoid spending a lot of time with the arm or leg hanging down.



PREVENTION of contractures

A child with an amputated leg does not use his leg normally. He usually keeps it bent, and he tends to develop contractures of the hip or knee (or both).

Therefore, special ***positioning*** and exercises are needed to prevent contractures and maintain full range of motion (see Chapter 43).



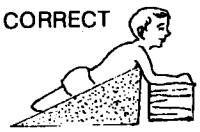
POSITIONS

Encourage positions that keep the joints stretched, and avoid those that keep the joint bent.

CORRECT



CORRECT



WRONG

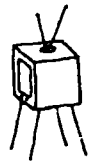


CORRECT



WRONG

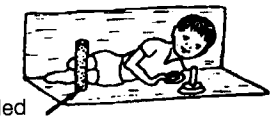




WRONG



CORRECT



padded post

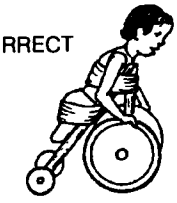
ONLY WHEN NECESSARY FOR MOVING ABOUT



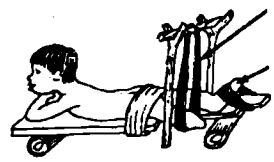
BETTER (But it can still cause hip contractures).



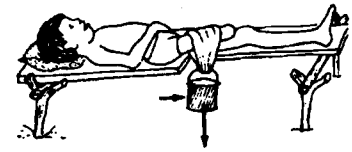
CORRECT



If contractures have already developed, try to position the child in ways that stretch them.

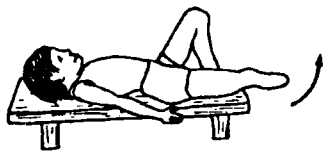


car tyre inner tube pulling joints straighter



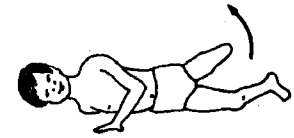
STRETCHING EXERCISES





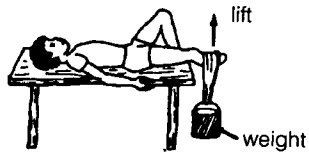
Be sure hips are straight

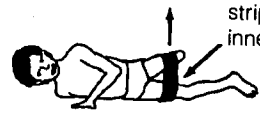




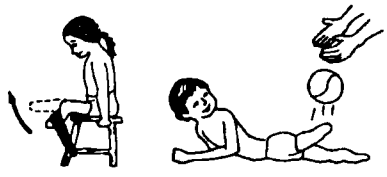
STRENGTHENING EXERCISES

Try to strengthen especially those muscles that straighten the joints, and those muscles needed for walking.

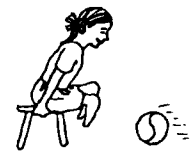


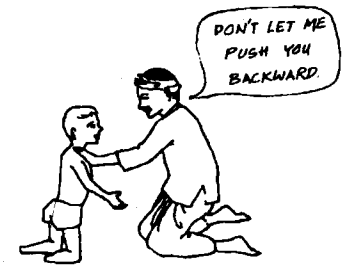




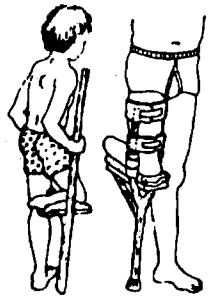






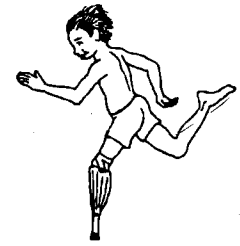


WARNING about walking aids



Walking aids or artificial limbs, like these, that keep the stump bent may be useful until the child can get a limb that keeps the joint straight.

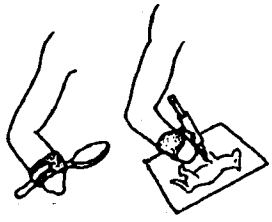
However, it is very important that the child do **stretching and strengthening exercises daily** if he uses a bent-joint aid.



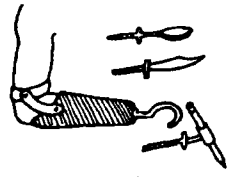
With a well-fitted stump-in-socket limb, normal activity usually provides all the stretching and exercise that are needed.

Instructions for making simple stump-in-socket limbs using bamboo and other local materials are in Chapter 68.

ALTERNATIVES FOR A CHILD WITH AMPUTATED HANDS



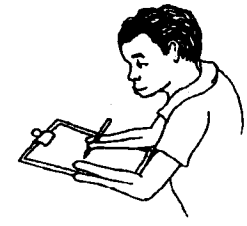
simple tool and utensil holders made of cloth, leather, or plastic (See p.330)



cuff with changeable tips



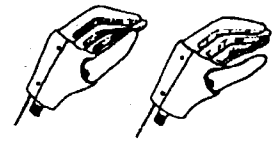
hooks that open and close to grip (operated by movements of shoulders and back)



surgery that turns the 2 bones of the forearm into pinchers

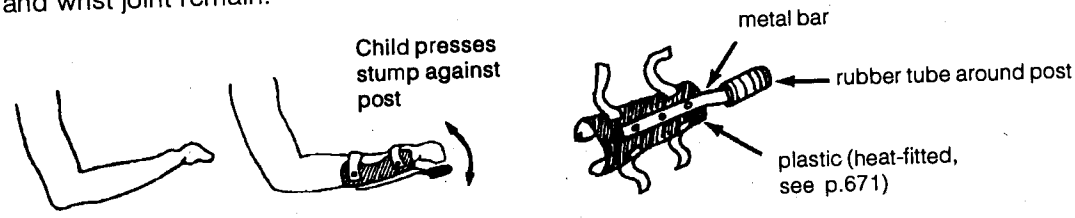


rubber or wood hand, not for use but for looks



instead of hooks, an artificial hand with a thumb that opens and closes against 2 fingers (expensive and may not last).

This is a grasping aid for a child whose fingers have been lost but the base of the hand and wrist joint remain.



The type of aid a child and her parents choose for an amputation will depend on several things, such as **availability, cost, usefulness, looks,** and **local cultural factors**. For help in choosing an appropriate aid, see Chapter 57, "Making Sure Aids and Procedures Do More Good Than Harm,", especially pages 644 and 645.

PREVENTION
CARE OF A SERIOUSLY WOUNDED LIMB

The proper care of a seriously wounded limb is important to prevent amputations. A child with a seriously wounded limb must be taken to a PHC (Public Health Centre), health post, or hospital as soon as possible. But before that, the simplest and best thing to do is to.

- clean the wound with ***clean water***
- then wrap it firmly with a ***clean*** cloth

If the child is loosing a lot of blood

- With a clean cloth (or your hand if there is no cloth) press directly on the wound if it is small but deep. Keep pressing until the bleeding stops. This may take upto 15 minutes (this may not be possible if the wound is very large).
- Raise the injured part of the body

If the bleeding cannot be controlled by pressing on the wound and if the person is still loosing a lot of blood

- Keep pressing on the wound.
- Keep the wounded part as high as possible.
- **If the wound continues to bleed or if the wound is very large.**
- With a clean cloth, duppatta or sari, tie around the arm or leg as close to the wound as possible on the side of the wound which is nearer the trunk. Tighten just enough to control bleeding.
- For the tie use a folded cloth. You can make a **wide belt** from a dupatta, or sari. Never use a thin rope, string or wire.
- Never tighten it very tight. This could damage the nerves.
- Loosen the tie for a moment every half hour to see if it is still needed and to let the blood circulate. **Leaving it too long may damage the arm or leg so much, that it may need to be cut off.**
- Do not use all your force in tightening the cloth, since a very tightly tied cloth can damage the nerves of the arm or leg and lead to paralysis or loss of sensation of the limb. ***(Adapted from Where There Is No Doctor)***



This man used brake oil to cover a wound caused by an agricultural implement. Instead of curing the wound, the oil will aggravate it leading possibly, to an amputation. ***Photo: Mathew Varghese***

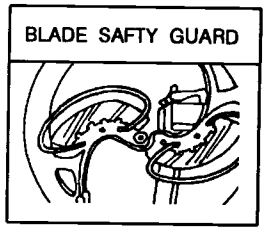
CAUTION: Tie the limb only if bleeding is severe and cannot be controlled by pressing directly on the wound.

Fodder cutters and amputation

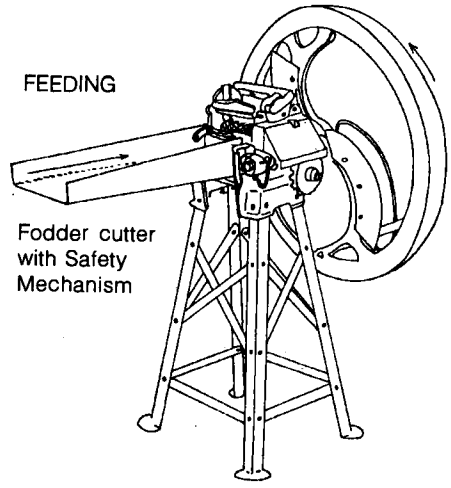
Fodder cutters are a significant cause of finger and hand amputations in children living in villages. This is a finding of a study conducted by a team of researchers in nine villages of Sonipat district in Haryana. The team found that forty five (45) percent of all fodder cutter injuries were caused to children upto 14 yrs of age.

In most cases, the child's finger was cut by the blade while playing with the machine while another rotated the flywheel.

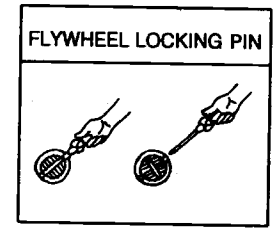
In other instances, hair and loose clothing got caught in the gears of the fodder cutter. Hands, caught while feeding the fodder into the rollers of the cutter, also resulted in injuries and amputations. The same team of researchers have now designed simple, sturdy and low cost safety mechanisms for fodder cutters, which will automatically protect against injuries and possible amputations.



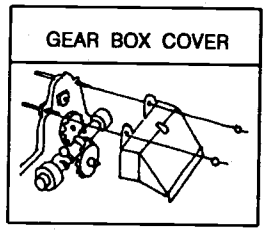
1. **Front safety guard:** A safety guard is fitted on each blade of the flywheel. This will push the limb away before the blade hits the limb. This would prevent injuries to children playing with machine and adults cleaning the blades or machine.



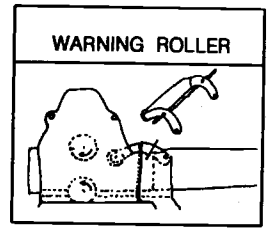
Fodder cutter with Safety Mechanism



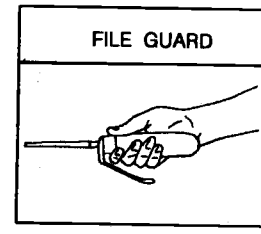
2. **Flywheel locking device:** A locking pin fixes the flywheel in place when machine is not being used. This reduces possibility of children getting their fingers cut inadvertently.



3. **Gear cover:** This low cost cover for gears will prevent clothes/ long hair of girls from getting entangled with the moving gears.



4. **File safety guard:** Finger safety guard fitted on the handle of file would prevent cuts even if the file slips while sharpening the blades.



5. **Warning roller:** This has been introduced on the feeding chute immediately before the feed rollers. This warns the operator that the hand has gone too far. The warning roller will not trap the hand and it gives the operator a chance to pull out his hand.

All the safety devices can be made by village level technicians. They are designed in such a way that they can be fitted on to most of the new and old fodder cutters.

For more details contact Dr. Dinesh Mohan and Dr. Rajesh Patel,
Center for Biomedical Engineering, Indian Institute of Technology, New Delhi.

NOTES

CHAPTER **28**

Burns and Burn Deformities

Serious burns occur in our country when people cook, warm themselves, or when children play near open fire. They are more common in overcrowded areas or overcrowded surroundings; where people live in crowded huts built of inflammable material; where kerosene pressure-stoves or open fires are used for cooking.

Burns are caused when heat is applied to the skin. This may be by open flames, hot liquids, steam and hot objects.

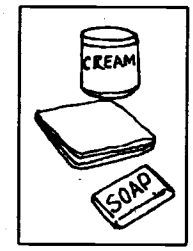
In children, burns are most commonly caused by hot liquids. This may be hot water for the bath, hot soap water for washing clothes, hot milk, hot tea or coffee, hot rice water, hot dal or liquid vegetables, etc.

The best first-aid is cold clean water, stored at room temperature. This can be drinking water from an earthen pot, water kept for a bath or any other clean water from a pond, tank, stream river etc. **Pour the cold clean water over the burned area till the burning sensation subsides. This may take upto 3 hours.** Cold water cools down the burned area and reduces the damage.

TO HELP BURNS HEAL: They should not be left open to the air. Germs in the atmosphere and other air borne particles may infect the burn and lead to pus formation.

The best thing to do is:

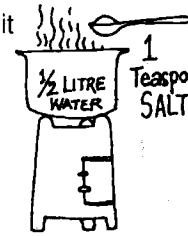
- Apply some cream or ointment to a clean piece of cloth or sterile gauze. Make sure your hands are clean when you do this.
- Apply this to the burnt area and secure with a bandage.
- Change the bandage everyday.



CAUTION: When you apply cream or ointment to the burnt area, make sure your hands are very clean. More damage is done to the burnt area by the application of all sorts of creams and ointments with dirty, unwashed hands.

If there is no cream or ointment available

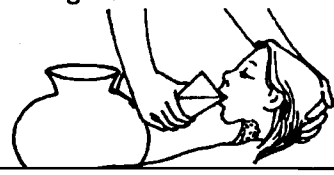
- Boil half a litre of water with one teaspoon of salt in it
- Apply this to the clean cloth or bandage
- Apply this cloth to the burnt area
- Change the bandage everyday







Children with severe burns should be encouraged to drink a lot of liquids.



The boiled potato peel dressing

The search has been on for many years to find a painless dressing for burn wounds. Normally dressings tend to stick to the burnt area and do not come off easily. This causes a lot of pain to the person.

The boiled potato peel dressing is now seen as an effective way of dressing burns. It is easy to make and low in cost.

How it is made

Since a large number of potato peels are needed, they can be collected from local hotels, canteens and hospitals kitchens. The peels are cleaned and then stuck to 4 inch or 6 inch wide roller bandages with starch paste. The paste is carefully applied to the outer surface of the peels before placing them edge to edge with no gaps. After the paste is dry, the bandages are rolled, labelled and placed in plastic bags. They are then sterilized by autoclaving (steam sterilization at 15° C for 30 minutes).

How it is used

'The bandage is moistened with saline water and smeared with silver sulfadizine ointment, or with soframycin in the case of children below 2 years and wrapped over the burnt area.

A single 6 inch potato peel bandage is enough to cover over 20–25 per cent burns in an adult person.

Cost

Each 6 inch potato peel bandage costs approximately Rs. 25/. If the cost of ointment and 4 to 6 gauze bandages is added to these it works out to approximately Rs. 50/- a day–a big saving when compared to costs of conventional bandages.

Some advantages:

- Conventional dressing sticks to the burns and peeling it off is painful. The person often has to be sedated with strong painkilling drugs. The potato peel dressings, do not stick to the burns and the formation of the delicate new skin on the burnt area is not hampered. There is no bleeding from raw surfaces when conventional dressing are peeled off. There is no need for painkilling drugs to take the bandage off. This is particularly good for young children.
- There is no need for bulky padding as used in the conventional dressing and this increases the child's ability to move around with ease.
- The dressing functions as a cover and protection from infection.

For more information contact:

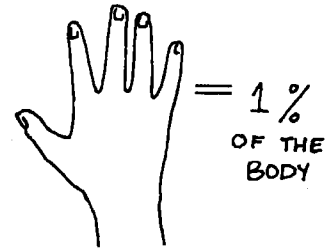
The Burns Association of India
103, Vijay Apartments
Bulabhai Desai Road
Bombay 400036
Tel : 4127000

The boiled potato peel bandages are being made and effectively used by Jubilee Mission Hospital at Trichur, Kerala.

WHEN SHOULD WE TAKE THE CHILD TO THE HOSPITAL?

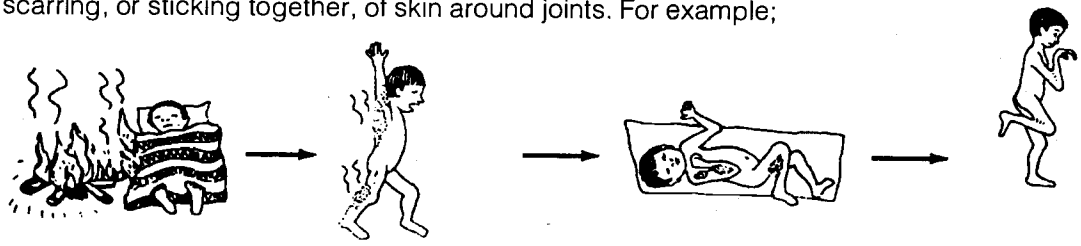
Burns of the face, hands, feet and genital areas and burns caused by electricity and chemicals are best treated in a hospital.

If a child has more than five percent burns on her body she should be taken to the hospital as soon as possible. A simple way to measure five percent of the body: One hand surface is equal to one percent of a person's body.



Common deformities

The most common deformities resulting from severe burns are contractures, and the scarring, or sticking together, of skin around joints. For example;



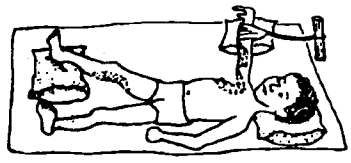
Kishan slept too close to the fire and his blanket caught fire.

He was badly burned under the arm and behind the knee

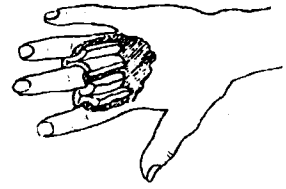
As he was healing, Kishan lay with his arm and leg bent. This kept the air away from the burns, and they hurt less.

But as a result, the skin scarred to itself. After the burns healed, Kishan could not lift or straighten his arm or straighten his leg.

TO PREVENT SCARRING TOGETHER OF THE SKIN AT JOINTS:



Keep the joints extended (straight) while the burns heal. You may have to support or tie the limbs so that the child does not bend them in his sleep.



For burns between fingers or toes, keep them separated with sterile cloth pads with Vaseline.



To keep the chin from scarring to the chest, it is very important to keep the head tilted up as the burns heal.

AFTER THE WOUNDS HAVE HEALED: Scars Occur. Large deep burns heal very slowly and form ugly stiff scars. Applying coconut oil and massaging onto the skin can prevent these scars. Reports from several parts of the world claim that fish oil on healed burns also helps prevent thick scarring and skin contractures.

An elastic bandage tied lightly will also help to prevent the thickening of scars. The bandage will also help to prevent contractures of the body.

RANGE-OF-MOTION EXERCISES

As soon as burns are covered with new skin or by a scar, gently begin range of motion exercises. Slowly straighten and bend the affected joint–a little more each day.

For exercise details, see Chapter 43. If scarring is severe, you may need to continue range-of-motion exercises for years after burns are healed. Scar tissue does not grow and stretch like normal skin. **Skin contractures** often form and may slowly get worse – sometimes even with exercises.

Before beginning exercises, it helps to rub oil into the healed burn (but never into a fresh burn). Oil helps prevent thick scarring and skin contractures.

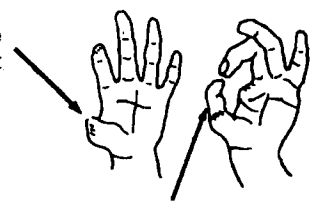
SURGERY

When joints are scarred down or severe contractures form after burns, 'plastic **surgery**' may be needed. Sometimes skin is taken from another part of the body and used to add more skin over the joint area (a skin transplant).

In case of severe burns that have destroyed fingers or thumb, special 'reconstructive' surgery may help to return use of the hand. (This surgery is very costly and usually can only be done by special surgeons in larger hospitals.)



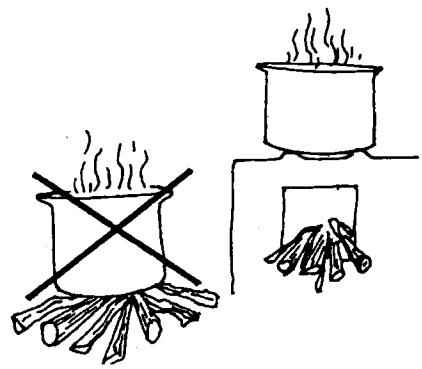
For example if the thumb has been destroyed, sometimes a finger (or toe) can be attached to the end of the stump so that the child can grasp things better.



index finger moved to form thumb

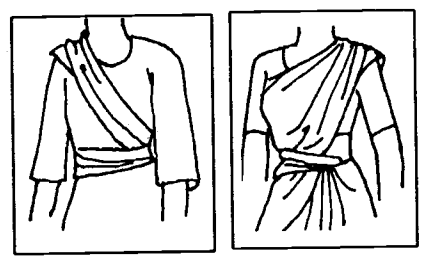
BURNS ARE BETTER PREVENTED THAN TREATED. The following points may serve as guidelines.

- Keep small children away from the kitchen or cooking area.
- Low level cooking is dangerous. Cooking on the platform is much safer.





- Keep hot liquids away from the reach of children.
- Teach children how to light a match safely. The match should be struck away from the body.
- Keep electrical points above the reach of children.
- Keep kerosene and other materials that catch fire easily, where children cannot reach them.



Teach young girls how to tuck their sari pallavs or dupatta safely, while they are cooking.

The unsafe use of fireworks has become a major cause of burns every year during the festival of lights–*Diwali.* A five year (1983-88) long study on the nature and extent of burns due to fireworks was conducted at the Lok Nayak Jai Prakash (LNJP) hospital of Delhi every year, and in other major hospitals of Delhi, Bombay, Pune and Rohtak.

The findings of the study showed that the largest number of burns were caused by the unsafe use of conical fountains. The conical fountain (Anar) seems safe and can easily be held in the hand while being lit. Most of the burns involved the hands and were caused by the firework exploding or flaring up in the hand while being lit.

Other fireworks such as bangers and rockets were dangerous because of the amount of explosives they contained. The amount of explosive will have to be limited if they are to be safely used.

The study was conducted by Dr Dinesh Mohan of I.I.T. Delhi and Dr. Mathew Varghese of LNJP hospital.

The Burns Association of India has issued special guidelines for preventing burn accidents during Diwali:

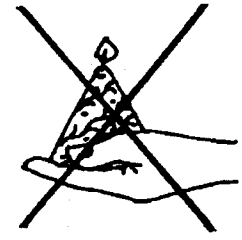
1. Light crackers that soar or zoom in an open space, eg. in a park, a playground or a terrace.



2. **Nylon burns easily, wear close fitting cotton clothes.**
   - Use bulbs in paper lanterns. Diyas are dangerous.
   - Do not experiment with crackers, ask your elders.



3. Do not hold conical fountains (Anars) in your hands to light them.



RESOURCES

Dr. Keswani
Child to child reader (watch out) VHAI
International child health
Vol II Number 3
July, 1991

NOTES

CHAPTER 29

Fits

Epilepsy

What are they ? Fits (also called seizures or convulsions) are sudden, usually brief, periods of unconsciousness or changes in mental state, often with strange jerking movements.



One out of every 10 or 20 children has at least 1 fit by age 15. But only 1 in 50 of these children goes on to have chronic fits (repeated fits over a long period of time) a condition known as **epilepsy**. About a half on these children will develop epilepsy before the age of 18 years. Epilepsy is known by different names in different parts of the country (mirgi, apasmara, moorche, isabu etc.)

CAUSES OF CHRONIC FITS (EPILEPSY)

Fits come from damage to, or an abnormal condition of, the brain. Common causes include:

- **Injury to the brain.** This causes at least 1/3 of epilepsies. Injuries may be before birth, during birth, or at any time after. The same causes of brain damage that result in cerebral palsy can cause epilepsy (see p. 101). In fact, **cerebral palsy and epilepsy often occur together. Meningitis** (Brain fever) is a common cause of this combination. In small children common causes of fits are **high fever** or **severe dehydration** (loss of liquids). In very ill persons, the cause may be **meningitis, encephalitis, malaria of the brain,** or **poisoning by lead and drugs** (see *Where There Is No Doctor*, p. 253–254). Epilepsy that steadily gets worse, specially if other signs of brain damage begins to appear may be a sign of a **brain tumor** (or of **hydrocephalus** in a baby–see p. 169). Fits caused by a tumor usually affect one side of the body more than the other. Rarely, fits may be caused by pork tapeworms that form cysts in the brain (see *WTND*, P. 344).
- **Hereditary.** There is a family history of fits in about 1/3 of persons with fits.
- **Unknown causes.** In about 1/3 if epilepsies, no family history or history of brain damage can be found.

Fever Fits. Children who have once had a fit with high fever will often have fits again when they have fever–especially if other persons in the family have had fits with fever. Be sure to check for infections of the ears and throat, as well as bacterial dysentery (diarrhoea with blood and fever), and **treat the cause.**

Fits that come only with fever usually stop occurring by the time the child is 7 years old. Sometimes they may develop into 'non–fever–related epilepsy', especially if the child has signs of brain damage (see "Cerebral Palsy," p.97 and 98).

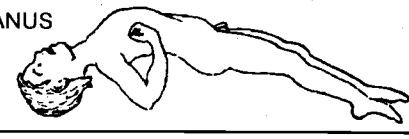
WARNING: Fits in a very ill child may be a sign of **meningitis**–for which immediate medical treatment is necessary to save his life. Learn how to check for signs of meningitis (see ***Where There Is No Doctor***, p. 264).

MENINGITIS



The spasms of **tetanus** can be mistaken for fits. The jaw shuts tightly (lockjaw) and the body suddenly bends back. Learn to spot early signs of tetanus (see ***WTND***, P. 260).

TETANUS



MORE ABOUT FITS (EPILEPSY)

Mental ability. Some children with epilepsy are intelligent. Others are mentally slow. Occasionally, fits that are very frequent and severe can injure the brain and cause or increase ***retardation.*** Treatment to control fits is important.

Types of fits. Fits may appear very differently in different children. Some may have severe, 'big' or 'major' fits with strong, uncontrollable movements and loss of consciousness. Others may have smaller or 'minor' fits. These can be 'brief spells' with strange movements of some part of the body. They can be sudden unusual behavior such as lip–sucking or pulling at clothes. Or they can be brief 'absences' in which the child suddenly stops and stares–perhaps with blinking or fast movement of the eyelids.

Some children will have both minor and 'big' fits or they may first have minor ones and later develop big ones.

Warning signs or 'aura'. Depending on the kind of fits, the child (and parents) may be able to sense when a fit is about to begin. Some children experience a 'warning' in which they may see flashes of light or colors. Or they may suddenly cry out. In one kind of fit, the 'warning' may be fear or imagined sights, sounds, smells, or tastes. In some kinds of fits there is no 'warning'. The child's body may suddenly jerk or be thrown violently. These children may need to continuously wear some kind of safety hat or other head protection.

Timing of fits. A child who has had a single fit need not have fits again. On the other hand, fits may happen weeks or months apart, or very often. Minor fits or 'absences' may come in groups–often in the early morning and late afternoon.

Fits are usually short. Minor fits may last only a few seconds. Big fits seldom last more than 10 to 15 minutes. Rarely, however, a child may enter into a long 'epileptic state' which may last hours. This is a medical emergency.

Some kinds of fits may appear at any age. Others begin in early childhood and usually disappear or change to other patterns as the child grows older.

Many persons have epilepsy all their life. Others begin in early childhood and usually, the fits disappear or change to other patterns as the child grows older. Usually, there is no need to know the exact kind of fits a child has. However, some kinds of fits require different medicines.

Effects of fits. During the fit the child may froth at the mouth and lose control of the bladder and bowel.

Fits may be followed by a headache, vomiting, dizziness, body ache, weakness, confusion and disorientation, lasting for a few hours or a day or so.

Sometimes a child may hurt himself or even bite his tongue during a fit.

WHEN ARE SPECIAL MEDICAL STUDIES NEEDED?

Doctors sometimes prescribe medication for fits without properly checking for signs of causes that may need attention. However, more and more doctors regularly order expensive testing such as an 'EEG' (electroencephalogram). Even if these services are 'free', they are often only available in a distant city, which causes the family much time and expense. Such tests do not usually help much in deciding treatment–unless a brain tumor is suspected. And even if it is a tumor, the possibilities of surgery or successful treatment may be very small, and the costs are often much too high.

A detailed description of the fit would be more helpful to the doctor for making a diagnosis.

The family and others should try and note the following details to tell the doctor.

- Note the time when fit started and when it ended.
- In what state was the child when the fit ended ?
- What was the child doing when the fit started ?
- What actually happened during the fit ?
- What kind of jerky movements did the child have and which parts of the body were involved ?
- Did the child hurt herself ?
- Did she lose bladder and bowel control ?

WHAT TO DO WHEN A CHILD HAS A FIT

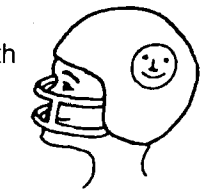
- Learn to recognize any 'warning signs' that a fit is about to begin, such as sudden fear or a cry. Quickly protect the child by lying her down on a soft mat or any other place where she cannot hurt herself. Do not panic. Most fits end spontaneously.
- When a 'big' fit starts, do not try to move the child unless she is in a dangerous place.
- **Protect the child as best you can against injury, but do not try to forcefully control her movements.** Remove any sharp or hard objects near her.
- **Put nothing in the child's mouth while she is having a fit**–no food, drink or medicine, nor any object to prevent biting of the tongue.
- Making the child smell a shoe or hitting him with the broom, or putting an iron object in his hands will not control the fit. Instead, it will disturb the child.
- **Between spasms, gently turn the child's head to one side**, so that spit drains out of her mouth and she does not breathe it into her lungs.
- After the fit is over, the child may be very sleepy and confused. She may have a bodyache and feel weak. **Let her sleep.**For **headache,** which is common after a fit, give acetaminophen (paracetamol) or aspirin.
- During a fit, the child may lose control over her bowel and bladder. Once the fit is over, clean her up and do not ridicule her later. She cannot help it.

HEAD PROTECTION

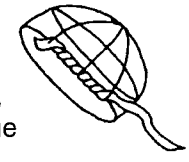
To protect the head of a child who falls hard when she has a fit, it may be wise for her to wear some kind of head protection most of the time.



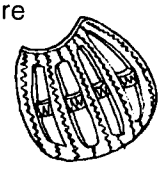
A child who often injures his face with fits may need a 'hard hat' helmet with a face mask.



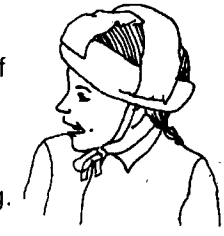
You can make a 'cage' of stiff wire and wrap it with strips of inner tube, soft cloth, or sponge rubber.



Or cut a piece of old car tire something like this.



Or sew strips of cloth filled with padding.



PREVENTING AND CONTROLLING FITS

There are no medicines that 'cure' epilepsy. There are no vaccinations to prevent epilepsy. However, there are medicines that can prevent the fits of most children–as long as they keep taking the medicine regularly. **As long as a child has epilepsy – which may be for years or all his life – he must continue to take anti – fit medicines.**

Sometimes preventing fits for a long time seems to help stop epilepsy permanently. For this reason, if the child has had many fits in the past, it is usually wise for him to keep taking anti – fit medicines regularly for at least three to four year after the last fit. Only then should you gradually lower and stop the medication to see if he still needs it.

It is very important that the medicines for fits are taken regularly. Irregular treatment results in poor control of fits. It helps to always keep a stock of medicines for epilepsy so that you are never caught unaware. Parents can set aside a time of the day when they are free to give their child her medicine. Keeping a daily chart also helps.





Choosing Medicines

Many different medicines are used for epilepsy. Some types of fits are controlled better by one medicine and some by another medicine, or by a combination of medicines. Some children's fits are easy to control. Others are very difficult. It may be necessary to try different medicines and combinations to find the most effective treatment. In a few children, no medicine will control the fits completely.

CAUTION: Great care is needed to select the medicines that help the individual child most, and which do her the least harm. If a child seems excessively sleepy, dizzy, slow–moving or looses interest in things,she may be getting too much medicine or wrong medicine. Consult a doctor immediately.

All anti-fit medicines are poisonous if a child takes too much. Be careful to give the right dose and to keep medicines out of reach of children.

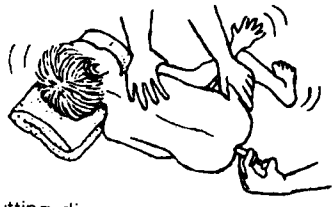
- Stopping or changing a child's medicine must be done gradually.
- Sudden stopping or changing the medicines may make fits worse. Also,it may take several days for a new medicine to have its full effect.
- Nearly all anti – fit medicines have side effects. Ask your doctor to explain the side effects of the medicine he prescribes for the child.
- The best medicine (or medicines) for a child with epilepsy is one that is effective, safe, cheap, easy to take and easy to get.
- Many of the anti-fit drugs, may increase the risk of birth defects when taken by a pregnant woman. Also, some of the drug goes into breast milk. Therefore, pregnant woman should use these drugs only when fits are common or severe without them. A woman should inform her doctor about her pregnancy so that he may prescribe safe anti–fit drugs to her.

TREATMENT FOR A LONG – LASTING FIT

When a fit has lasted more than 15 minutes:

- if someone knows how, inject IV diazepam (Valium) or phenobarbital **into the vein.**
- or put a 'suppository' of diazepam, paraldehyde, or phenobarbital up the rectum.

> *NOTE:* these medicines do not work as fast or well when they are injected into a muscle. If you only have injectable or liquid medicine, put it up the rectum with a plastic syringe without a needle. Or grind up a pill of diazepam or phenobarbital, mix with water, and put it up the rectum.

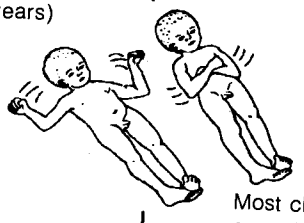


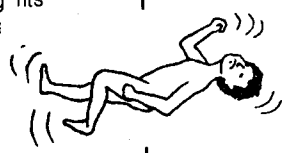
Putting diazepam up the rectum works faster than injecting it into a muscle.

If the fit does not stop in 15 minutes after giving the medicine, repeat the dose. **Do not repeat more than once.**

Types of epileptic fits

Note: This information is for rehabilitation workers and parents so that they may learn to recognise the different types of fits. It is adapted from ***Current Pediatric Diagnosis and Treatment*** by Kempe, Silver, and O'Brien (Lange Medical Publishing), in which more complete information is provided.

TYPE	AGE FIT BEGINS	APPEARANCE	TREATMENT
Newborn fits 	birth to 2 weeks	Often not typical of later fits. May show sudden limpness or stiffness; brief periods of not breathing and turning blue; strange cry; or eyes roll back; blinking or eye–jerking; sucking or chewing movements; jerks or strange movement of part or all of body.	Phenobarbital or phenytoin. Add diazepam if not controlled. (Fits due to brain damage at birth are often very hard to control.)
Baby spasms (West's syndrome) 	3–18 months (sometimes 4 years)	Sudden opening of arms and legs and then bending them–or repeat patterns and/or uncontrolled movements usually appear months later, but the baby not lose consciousness. Most children with these spasms are retarded.	Corticosteroids may be tried-but are dangerous. Try to get help from an experienced doctor or health worker. Valproic acid or diazepam may help.
Fever fits t (fits that only occur when child has a fever 	6 months to 4 years	Usually 'big' fits (see next page) that happen only when child has a fever from another cause (sore throat, ear infection, bad cold). May last up to 15 minutes or longer. Often a history of fever fits in the family. Only a few of these children have epilepsy in later life. *WARNING:* Look for signs of meningitis.	A child who has had fever fits on several occasions should be treated with phenobarbital continuously until age 4 or until one year after the last fit- Fits usually do not continue in later childhood.

TYPE	AGE FIT BEGINS	APPEARANCE	TREATMENT
Jolt or a 'lightening bolt' fits (Lennox–Gastaut syndrome) 	any age but usually 4–7 years	Sudden violent spasms of some muscles, without warning, may throw child to one side, forward, or back ward. Usually no loss of consciousness, or only brief. Many children also suffer from 'big' or generalized fits. May be a history of 'baby spasms'(see above) in earlier childhood.	Try phenobarbital, with valproic acid. If no improvement, consider trying corticosteroids as in baby spasms, or other medicines with medical advice. Protect child's head with head-gear and chin padding. 
Blank spells or 'absences' (petitmal) (This typeof fit alone is rare 	3–15 years	The child may be mentally retarded. Child suddenly stops what she is doing and briefly has a strange, empty of 'bank' look. She usually does not fall, but does not seem to see or hear during the fit. These 'absences' usually happen in groups. She may make unconscious movements, or her eyes may move rapidly or blink. These fits can be brought on by breathing rapidly and deeply. (use this as a test.) Often confused with 'psychomotor' fits, which are much more common.	Valproic acid or ethosuximide. Since many children also) have 'big' fits, add phenobarbital if necessary (or try it first if you think the fits might be 'psychomotor' –see below).
'Marching'fits (Focal fits) 	any age	Movement begins in one part of the body. May spread in a certain pattern (Jacksonian march) and become generalized.	Phenobarbital or Phenytoin (or both)- If poor results, try carbamazepine or primidone.
Mind–and– body fits (psycho–motor first) 	any age	Starts with 'warning' signs: sense of fear, stomach trouble, odd smell or taste, 'hears' or 'sees' imaginary things. Fit may consist of an empty stare, strange movements of face, tongue or mouth, strange sounds, or odd movements such as picking at clothes. Unlike 'blank spells', these fits usually do not occur in groups but alone and they last longer. Most children with psychomotor fits later develop 'big' fits.	Try phenobarbital first -then phenytoin, or both together, then carbamazepine, or all 3 together. Valproic acid may also be useful. Or primidone instead of phenobarbital. Psychological counseling sometimes also helps-
Generalized or 'big' fits (gr 	any age	Loss of consciousness– often after a vague warning feeling or cry. Uncontrolled twisting or violent movements. Eyes roll back. May have tongue biting, or loss of urine and bowel control. Followed by confusion and sleep. Often mixed with other types of fits. Often family history of fits.	Try phenobarbital first. Then phenytoin. Then carbamazepine-or combinations. Or combine primidone or methsuximide with one or more of the others.
Temper tantrum fits (not really epilepsy) 	under 7 years	Some children in 'fits of anger' stop breathing and turn blue. Lack of air may cause loss of consciousness briefly and even convulsions (body spasms, eyes rolling back). These brief fits, in which the child turns blue before losing consciousness, are not dangerous.	No medical treatment is needed- Use methods to help the child improve behavior (see Chapter 41).

HELPING THE COMMUNITY UNDERSTAND EPILEPSY

It is important for members of the community to know that anyone can get epilepsy. Epilepsy does not strike any particular caste or creed. A child who has had a single fit may not suffer from recurrent fits. Fits can occur at any age and at any time of the day or night, when a person is asleep or when he is awake.

Epilepsy is not the result of witchcraft or the work of evil spirits, as many people would believe. It is often children who have big or major fits who suffer the most. They are said to be possessed by the devil and are shunned by the community.

- Epilepsy is not a sign of madness nor is it the result of bad actions by the child or his parents or ancestors. Epilepsy is not an infectious disease, and cannot be caught or spread to other people.

- Marriage will not cure epilepsy. Often people feel that once a person marries he will not get any more attacks.

- Branding a child with epilepsy is an old and cruel practice that still exists. The belief in some communities is that a lot of air gets into the body of the child. It churns inside the stomach and it is this churning that causes the fit. They believe that branding with red hot iron will help the air come out. But neither branding nor exorcism, can cure or even prevent a fit.

- Some people believe that epilepsy is the result of a cold. The child is prevented from eating cold foods to avoid further attacks. But even this does not help, since epilepsy is not caused by a cold.

All these beliefs result in the social isolation of a child or adult with epilepsy.

It is important for members of the community to know that anyone can get epilepsy. It does not strike any particular caste or creed.

A child who has had a single fit may not suffer from recurrent fits.

Fits can occur at any age and at any time of the day or night, when a person is asleep or when he is awake.

Although children with epilepsy should be encouraged to lead active, normal lives, certain precautions are needed – especially for children who have sudden fits without warning. other children can learn to help in the safety of such a child – especially at times when danger is greatest.

EPILEPSY IN THE SCHOOL

Most children with fits can be in a normal class or school as they have the same intelligence and educational potential. Some may need special education usually not because of the epilepsy itself but because of associated handicaps.

Sometimes a disability is imposed on the child by the attitudes we have. Improved communication between the child, his parents, teachers and friends can help a lot.

Sometimes, having epilepsy may affect the learning and progress of a child in school. Teachers, parents and friends must understand these reasons since many of them are preventable.Sometimes, teachers and parents do not expect much from a child who has fits. They may treat him differently from other children in the class, even though he has the same

level of intelligence. This can affect the child.

If seizures are likely to occur in the class, the schoolteachers and other children should learn about epilepsy and how to protect a child when she has a fit. If they learn more about epilepsy it will help them to be supportive rather than afraid or cruel. (See CHILD–to–child activities, p. 521.)

A child who has fits frequently may not attend school regularly and this can affect his performance. Teachers and friends can take care not to send the child home from school, if the attacks are brief and the child recovers fully.

Incorrect or excessive drug treatment can also affect the child's performance in school. Sedative drugs hamper learning and concentration and also affect movement in some children. If this is happening the child should be taken to a health worker or a doctor. A change of medicine may be needed.

PREVENTION of epilepsy

1. Try to avoid causes of brain damage–during pregnancy, at birth, and in childhood. This is discussed under prevention of cerebral palsy, p. 121.

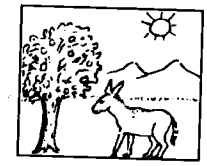
2. Avoid marriage between close relatives, especially in families with a history of epilepsy.

3. When children with epilepsy take their medicine regularly to prevent fits, sometimes the fits do not come back after the medicine is stopped. To make it more likely that fits will not come back, be sure that the child takes her anti-fit medicine for at least 3 to 4 years after her last fit. (Often, however, fits will still return when medicine is stopped. If this happens, the medicines should be taken for at least another year before you try stopping again.

CHAPTER 30

Blindness and Difficulty Seeing

Difficulty with seeing can be mild, moderate, or severe. When a person sees very little or nothing, we say he is blind. Some children are **completely blind;** they cannot see anything. However, **most blind children can see a little**. Some can only see the difference between light and dark or day and night, but cannot see any shape of things. Others can see shapes of large objects, but none of the details.



what a child with normal sight can see

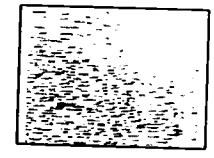
Many more children are not blind but do have some **problem seeing things clearly**. For example, they may see fairly well for most daily activities, but have trouble seeing details. The family may not realize that the child has a seeing problem until they notice she has difficulty threading a needle, finding head lice, or reading letters on the blackboard at school. Often these children can see much better with eyeglasses or a magnifying glass. Children who are completely blind cannot see at all, even with eyeglasses.



what a partly blind child may see (large forms but no details

Some children are born blind. Others become blind during early childhood, or later.

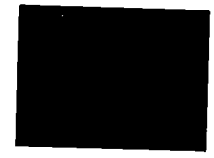
> ***CAUTION:*** Not all children who are blind have eyes that look different. Their eyes may look clear and normal. The damage may be behind the eyes or in part of the brain. So be sure to watch for other signs that can tell you if a child has difficulty seeing.



what a child sees who can only tell the direction a bright light is coming from

SIGNS THAT COULD MEAN A CHILD HAS A SEEING PROBLEM

- Eyes or eyelids are red, have pus, or continually form tears.
- Eyes look dull, wrinkled, or cloudy, or have sores or other obvious problems.
- One or both pupils (the black center of the eye) looks gray or white.
- By 3 months of age, the child's eyes still do not follow an object or light that is moved in front of them.
- By 3 months the child does not reach for things held in front of him, unless the things make a sound or touch him.
- eyes 'cross', or one eye turns in or out, or moves differently from the other. Some eye-crossing is normal up to 6 months).
- Child squints (half shuts his eyes) or tips head to look at things.
- Child is slower to begin using his hands, move about, or walk than other children, and he often bumps into things or seems clumsy.
- Child takes little interest in brightly colored objects or pictures and books, or she puts them very close to her face.
- Has difficulty seeing after the sun sets (night blindness).
- In school, the child cannot read letters on the blackboard. Or he cannot read small print in books, or gets tired or often gets headaches when he reads.



what a completely blind child sees

If the child shows any of these signs, test her vision, and if possible, see a health worker or eye doctor. Sometimes eyesight can be saved by preventive steps or early treatment (see p.293).

Methods for **testing if a baby sees** and for **measuring the vision of children** are discussed with **Child-to-child activities on p. 546 and 547.**

Blindness with other disabilities

Some children with cerebral palsy or other ***disabilities*** are also partly or completely blind. Parents may not realize this and think that the child's slow development or lack of interest in things is because he is mentally and physically handicapped. In fact, blindness may be a large part of the cause.

Even if a child has no other disability, **blindness can make development of early skills slower and more difficult. If the child does not look at, reach for, or take interest in things around him, check if he can see (and hear).**

> ***Note:*** Some children with severe brain damage or mental retardation may seem blind. They may look at things without really seeing them, because their brains are at the developmental level of a newborn baby. With lots of stimulation, little by little some of these children begin to become more aware of things, to follow them with their eyes, and finally to reach for them.

Causes of blindness

Different people have different beliefs about what causes blindness. In some parts of the world, people think a child is born blind as punishment for something the parents have done. This does not really cause blindness. Majority of blindness is acquired. **Child blindness is usually caused by poor nutrition or infection,** and that **most blindness in children can be prevented.**

COMMON CAUSES OF BLINDNESS IN CHILDREN

1. **'Dry eyes'** Xerophthalmia, or nutritional blindness is the most common cause of child blindness. It is especially common in parts of Africa and Asia. In India, as many as 30,000 children are affected by nutritional blindness every year. It results when a child does not get enough vitamin A, which occurs naturally in many fruits and vegetables and also in milk, meat and eggs. Dry eyes develops in children who are not regularly fed any of these foods. Also during acute infections, the vitamin A status of the child becomes worse. Measles, a common childhood infection is often one of the major causes of nutritional blindness. Acute respiratory and gastrointestinal infections such as whooping cough, tuberculosis and diarrhea also aggravate the vitamin A deficiency in a child. Intestinal parasites especially round worms are common among children belonging to poor communities. The incidence of vitamin A deficiency is higher among children who have round worms in their gastrointestinal tracts. Dry eyes appears quickly and gets worse when children who are deficient in vitamin A get any one of these infections. It is also much more common in children who are not breast fed.

SIGNS OF XEROPHTHALMIA

First sign may be night blindness. Child sees worse than others in the dark.



Next the eyes look 'dry'. The white part loses its shine, begins to wrinkle, and forms patches of little gray bubbles Bitot's spots).



Later, the dark part (cornea) also gets dry and dull, with little pits.



Finally, the cornea may get soft, bulge, or burst, causing blindness.



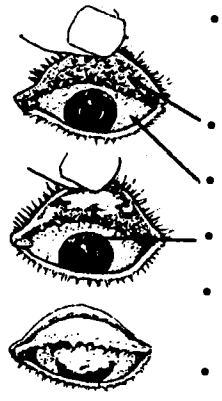
Traditionally in some areas, women and children get very little quantities of vitamin A in their diets. In some areas it is believed that children should not be given green leafy vegetables as this may cause diarrhea. Many communities in the south and the north of India believe that papaya, a fruit rich in vitamin A should not be eaten by pregnant women.

2. Trachoma is the commonest cause of preventable blindness in the world. It often begins in children and may last for months or years. If not treated early, it can cause blindness. It is spread by touch or flies and is most common in poor crowded living conditions.



Trachoma can often be prevented by keeping the child's eyes clean and keeping flies away. To prevent blindness from trachoma, treat early with tetracycline eye ointment or, *(Where There Is No Doctor,*) p. 306)

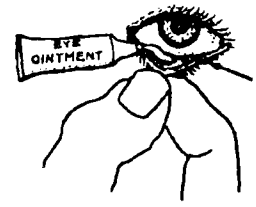
SIGNS OF TRACHOMA



- begins like 'red eye' with red, watery,sore eyes. Or in children it may develop for months with few or no early signs.
- After a month or more small lumps form inside the upper eyelids.
- White of the eye becomes inflamed or swollen.
- Top edge of the cornea may look cloudy.
- After years the lumps inside eyelids begin to go away, leaving whitish scars.
- The scars may pull the eyelashes down into the eye, scratching the cornea and leading to blindness.

3. Gonorrhea in the eyes of newborn babies causes blindness if not treated immediately. The baby gets the infection from his mother at birth. The eyes get red, swell, and have a lot of pus. It can be prevented by putting tetracycline eye ointment or a drop of 1% silver nitrate solution in the eyes of all babies at birth. Gonorrhea, which is a very common venereal (sexually spread) disease, can sometimes be treated with penicillin (see *Where There Is No Doctor,* p. 307 and 356).





Put the ointment inside the lower lid.

4. **'Chlamydia'** is a venereal disease caused by the same virus as trachoma. It is similar to gonorrhea, both in the genitals and the eyes, and is rapidly spreading worldwide. Putting tetracycline ointment in the eyes of a newborn baby 3 times a day for 3 days usually prevents eye damage from both gonorrhea and chlamydia.

5. Measles, which can injure the surface of the eyes, is a common cause of blindness especially in Africa, and in children who are poorly nourished.

6. Brain damage causes blindness in many children, usually in combination with cerebral palsy or other disabilities. Brain damage can happen before, during, or after birth. Causes include German measles during pregnancy, delayed breathing at birth, and meningitis. (See p. 101).

WARNING



Running with a pointed object is DANGEROUS TO THE EYES

7. Eye injuries often cause blindness in children. Common cases include pointed tools, fireworks, acid etc. Children playing with sharp edged toys such as bow & arrows, people working in occupations such as glass factories, stone quarries, firework factories etc. run the risk of becoming blind.

8. Also, blindness in children is sometimes caused by other problems such as hydrocephalus (see p.195), arthritis (see p.155), leprosy (see p. 258), brain tumors, or certain medicines (see p. 295). Cataracts (clouding of the lens inside the eye) gradually develop in about half of older children with Down Syndrome.

PREVENTION

Colostrum, the thick milky secretion of the breast in the first few days after childbirth is a very rich source of vitamin A. Infants fed with colostrum have better reserves of vitamin A.

1. Dry eyes can be prevented by feeding (foods rich in vitamin A) to children, pregnant and lactating women. Encourage families to grow and eat things like squash, carrots, papaya and green leafy vegetables. Be sure the child eats these foods regularly, beginning at 4 to 6 months old.
2. Fat or oil also helps in the absorption of vitamin A in the body. So include some fat in the child's diet, along with leafy vegetables.
3. Continue to feed children ill with diarrhea, measles, respiratory and other serious infections with the usual food, including dark green leafy vegetables and yellow orange fruits. Vitamin A capsules can also prevent dry eyes, but should not take the place of a well balanced diet. Give 2,00,000 i.v. of vitamin A (60 mg. retinol) once every 6 months or 100,000 units to babies less than 1 year old. Do not give this large dose more often that 6 months, because too much vitamin A can poison a child. For treatment, give 200,000 i.v the next day, and 200,000 i.v. 2 weeks later. See a health worker.

FOODS THAT ARE RICH IN VITAMIN A.

a) Green Leafy vegetables such as:

1. Spinach *(Palak)*
2. Batina Saag
3. Amaranth leaves *(Thotakura)*
4. Drumstick and Drumstick leaves
5. Gogu leaves *(Gongura)*
6. Mint *(Pudina)*
7. Fenugreek leaves *(Methi)*
8. Onion stalk
9. Cow pea pod
10. Rape plant leaves
11. Mustard plant leaves *(Sarson Saag)*
12. Beetroot leaves
13. Arvi leaves
14. Radish (red and white) leaves *(mooli leaves)*
15. Carrot leaves *(Gajar)*
16. Coriander leaves *(Dhania).*

Green leafy vegetables are a rich source of carotene which gets converted in the body to form vitamin A. They are also an extremely rich source of iron.

b) Yellow and red fruits and vegetables

1. Tomatoes
2. Mango
3. Papaya
4. Pumpkin
5. Orange

c) Milk and milk products, egg yolks, fish, liver and kidneys.





Measures that the community can take to ensure that there is enough vitamin A in the diet

- Small farmers can be encouraged to grow yellow fruits and green leafy vegetables as a part of income generation activity.
- Oilseed, spice and fibre crops like rape/mustard *(Sarson)* coriander *(Dhania)* and fenugreek *(Methi)*, Rajkheera and Mesta are cultivated as commercial crops over large areas for their seeds. **The leaves of these crops are edible and rich in Vitamin A. Careful harvesting of the leaves from these crops without affecting the seed yield can be a good potential source of Vitamin A for the community.**
- Vegetables and fruits rich in Vitamin A can be encouraged to be grown as intercrops in paddy, wheat and sugarcane fields.
- Trees such as Drumstick and Agathi can be a part of the tree planting activity of the community as the leaves of these trees are a rich source of Vitamin A.

Adapted from NFI Bulletin July, 1991.

WARNING ON USE OF EYE MEDICINES

Only use modern medicines or 'home cures' that you are ***sure*** cannot damage the eyes.

One modern medicine that should not be used often, and only with great caution, is **corticosteriod eye ointment**. Some doctors and health workers prescribe it for almost any eye irritation. **This is a dangerous mistake**. If the irritation is caused by a virus (tiny germ), this ointment could make the infection worse and lead to eye damage or blindness!*

Some 'home cures' for eye problems are safe and effective. For example, in mexico when villagers get a small piece of dirt or sand in the eye, to remove it they put a wet **chia seed** under the eyelid. The smooth seed has a layer of sticky mucus on it, to which the dirt sticks. Then they remove the seed. This is a safe, good home cure.



chia seeds–a helpful home cure

Some home cures are dangerous. Some villagers try to treat 'blurred vision' by putting human feces (shit) around the eye. This is unsafe and does not help. It could lead to dangerous infection. It is also dangerous to put lemon juice, urine, pieces of abalone shell, or *Vicks* ointment in the eye.



putting feces around the eye–a dangerous home cure.

**Note:* Corticosteroid drops or ointment are important medicine for preventing blindness from iritis (see "Arthritis" and "Leprosy"). But tests with 'fluorescein' should be done first to be sure there is not a virus infection. Get medical advice.

What is the future for a blind child?

With help and encouragement from family and community, a child who is blind can usually develop early skills as quickly and as well as other children. He can learn to feed, bathe, dress and care for himself, and to find his way around the home and village without help. Although he cannot see well, he develops an **outstanding ability to use his sense of hearing, touch, and even smell.**. If he can see at all, he can be helped to make the best use of whatever vision he has. He can and should go to school. Although he may not be able to read ordinary writing, he can develop his memory.

As he grows up, he can become a farmer, or a crafts person. And if he has the opportunity for training, he can learn any of a wide variety of skills. Where blind persons are given a fair chance, they often take active part in their communities and can live full, happy lives. In many countries, blind people have been leaders in organizing disabled persons to become more self-reliant and to work toward their rightful place in society.

Unfortunately, blind children often are not given a chance to develop as quickly or as fully as they could. In some countries more than half of the children who are born blind die of hunger or neglect before they are 5 years old. Also when people live with the belief that blindness is a curse or punishment for a sin, they do not seek help. On the next page are 2 stories of blind children that will help you realize the difference that understanding and help from family and community can make.

SHANTI*

Shanti is a little blind girl, who was born in a small village in India. When they found that she was blind, her parents and grandparents tried to hide the fact from the other villagers. They thought all blindness was sent to a family as a punishment for sin, and that people would look down on them.

Secretly her parents took Shanti to an orphanage and left her there.

Nobody in the orphanage had ever cared for a blind child, and they did not know what to do. There were so many other children who needed care, that there was no time left for her.

Shanti was kept alive, but that was all. Nobody talked to her or held her lovingly or tried to stimulate her. Her blind eyes made the nurses think she could not understand or recognize anything around her. So when other babies began to reach out for objects they saw, and then to crawl toward things they wanted. Shanti was left lying silently on her cot.

People got used to the blind child. She was picked up when necessary, and cleaned and fed. They fed her with a bottle, or pushed food into her mouth. But nobody tried to teach her how to feed herself or how to walk and talk.

As she grew older, Shanti spent most of her time sitting on the doorstep, rocking herself and poking her eyes (see p. 446). She never said a word and only cried when she was hungry. Other children stayed away from her; they were afraid of her dead eyes. Everyone thought she was mentally retarded and that nothing could be done about it.



In time, Shanti did begin to talk and walk. But the sad, stony look on her face never disappeared. Now, at age 7 she is in some ways still like a 2 year old. And in other ways she is no longer a child. We can only guess at her future.

*Story adapted from ***How To Raise a Blind Child***, see p.771.

RANI

Rani is also a little blind girl, born in another village in India. Like Shanti's family, when her parents learned she was blind, they were worried about what the villagers would say. But the baby's grandmother, who had slowly lost her sight 5 years ago, said, "I think we should do everything we can for the baby. Look at me. I,too,am now blind, and yet I still have all the same feelings and needs as I did when I could see. And I can still do most of the things I used to do. I still bring water from the well, grind the rice, milk the goats...".

"But you could already do all those things before you went blind," said the father, "How could a blind baby learn?"

"We must help her learn," said Grandma, "Just as I've learned to do things by sound and touch, so Rani must learn, I can help teach her, since I know what it's like. But we can also get advice from the health worker,".

The village health worker came the next day. She did not know much about blindness., but she knew a little about early child development. She suggested they give the baby a lot of stimulation in hearing and feeling and smelling things, to make up for what she could not see. "And talk to her a lot,", she said.

The family took the advice. They put all kinds of things in Rani's hands and told her what they were. They gave her bells and squeakers, and cans and bottles to bang on. Grandma, especially, took Rani with her everywhere, and had her feel and listen to every thing. She played games with her and sang to her. At age 2, Grandma taught her to feel her way along the walls and fence, just as she did. By age 3 , Rani could find her own way to the latrine and the well. When she was 4, the health worker talked with the neighbors, and did some CHILD-to-child activities on blindness with their children. After a few children came to make friends and play with Rani. Sometimes they would all blindfold their faces and try to find something or tell different things apart. At these games, Rani usually won.

When she was 6, Rani started school.The neighbor children came for her everyday. When the villagers saw them all walking down the road together, it was hard to guess which one was blind.



Early stimulation

As Rani's grandmother realized, a child who is blind has all the same needs as other children. She needs to be loved, not pitied. She needs to get to know the members of the family, and other things, by touch, sound,smell, and taste. The whole family can help her to become more aware of her home, and the things that are going on around her.

A baby's first plaything is her own body. Since she cannot see her hands and feet move, you may need to help her to feel, taste, smell, and explore them.

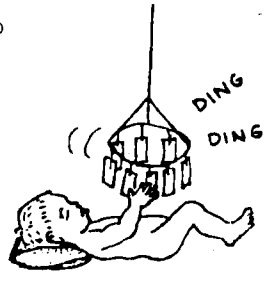


Have him compare by touch and sound his own and other people's faces so that he begins to recognize different people.

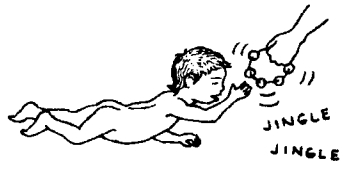


Activities to help a child develop early skills more quickly are discussed in Chapter 36, p, 371 to 389. Most of these activities can help a blind child. But **because he cannot see, he will need more stimulation in other areas, especially sound and touch, and in beginning to reach toward things and move about.**. Use toys and playthings that have many different shapes, feel different to touch, and make different sounds (see p. 563 to 572).

At first you may need to place the toy in the child's hand, or guide his hand to it. Or hang different things near him so that when he moves his hands they touch them.



At each stage of the child's development, attract her attention with
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Praise her when she does well or tries.

In addition to special activities, **be sure the child spends most of each day in a situation where she can keep learning about people and things.**. In everything you do, **talk to her**, tell her the names of things, and explain what you and she are doing. At first she will not understand, but your voice will let her know you are near. Listening to words and names of things will also prepare her for learning language skills.

Talk to the child as you do housework.

Tell her what makes the sound she hears.

Talk to her normally and look at her while you talk to her.



Sing to the child and encourage him to move to music.

Also encourage blind children to make their own music.



For ideas on homemade musical instruments see p.563.



Take the child outside often to the market, the river, the cowshed, the village square. Show and explain different things to him, and tell him what makes different sounds.

For a blind child, it is important that special help and stimulation start early-in the first months of life. Without this the child will fall far behind in her development. For example she may not sit, stand or even speak at the same time as other children. She may become quiet, not do much, and be afraid to move about. So her family does not expect much of her, or provide many learning opportunities. As a result she falls still farther behind. This does not mean that the child is slow or mentally retarded. It only means that because of the lack of sight, the child has not been able to learn the activity well enough.

However, **if a blind child has the stimulation and help she needs from an early age, she will develop ,many skills as quickly, as a child who sees**. So her family expects more of her and includes her more in their activities. As a result, she may develop almost as quickly as other children her age. She can probably enter school when they do.

Helping the blind child learn to move about

The child who is blind often is slow at learning to move about and will need extra help and encouragement. Some of the activities in Chapter 36 for creeping, crawling, standing, and walking will help. Here are some other suggestions.

When the child is beginning to scoot or crawl, you can leave toys and other interesting things in different places where he will find them. This will encourage him to explore and discover.

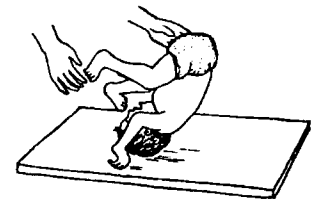


But when the child begins to walk, try to keep everything in its place, so that she does not bump into things unexpectedly and gain more confidence moving about. If you change the position of something, show her where it is.

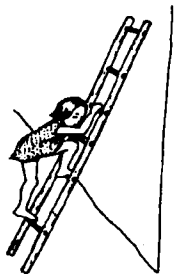


Play games and do exercises that will help the child gain confidence in moving and using his body.

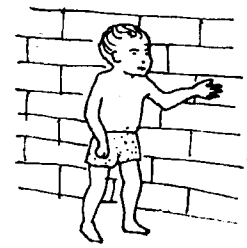




Encourage the child to adventure, explore, and do all the things a child normally does. Protect her from hurting herself–but do not protect her too much. Remember, all children learning to walk sometimes fall. A blind child is no different.







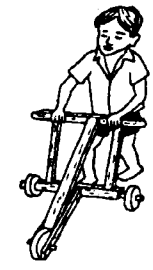
Help the child find his way by following walls and fences.

The child can learn to feel the edge of the path with her feet, and to feel plants or other objects with her hands.



If the child does not start walking without help, let him start by pushing a simple walker,chair or cart.

Do not force the blind child to walk alone before he is ready. One day he will start walking alone, first a few steps only, but finally with confidence.



Helping the blind child find her way without holding on

Outside the home, often a blind child will let you lead her by the hand, but may be afraid to take steps or try to find her way alone.

To help her begin to walk alone, first lead her over the area where you want her to walk. Show her and let her feel the different landmarks (posts, trees, bushes, houses) with her hands and feet along the way.

A good way to guide a child by the hand is to let him hold one finger and walk a step behind you.



Now walk over the same path, but this time walk backward in front of him, and talk to him while you are walking.



When he feels comfortable with your walking in front of him, start walking behind him. Have him tell you the landmarks

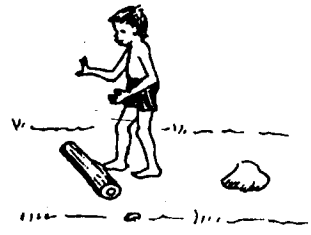


Little by little make yourself less and less needed. Speak less and let her go farther away from you.

Help her also to identify places and landmarks by using her sense of smell. For example she can learn to tell where the manure pits are by learning to recognize the distinctive smell of manure. Help her also to listen to recognize landmarks by sound. For example help her to recognize where the stream is by the sound of running water. She can learn to recognize the temple by the sound of the chiming bells.

Finally let her go the whole way alone. Start by having her walk short distances. Then gradually go farther, with more turns and other things to remember.

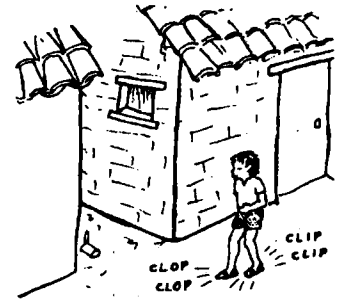
When she has progressed this far, the child will have the joy of knowing she can solve some problems alone. She will be ready to learn new things, meet other difficulties, and explore new areas.



The child needs to learn to 'see' with her feet, and to be prepared for unexpected things in her way. Play games with her. Tell her you have put some things in her path. See if she can get past them without slipping or falling.

Sometimes the child will fall. Have her practice this by falling on soft ground. Teach her to put out her hands and bend her knees as she falls. She will be less likely to hurt herself.



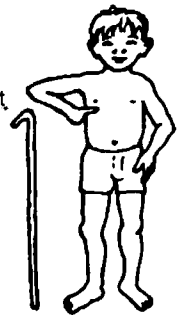


Help the child to recognize how the sound of her footsteps (or her stick) changes when she is near a house or wall, and when there is open space. With practice, she can learn to tell the distance from things by the sounds.

Learning to use a stick

Using a long stick can help a child find his way and give him more confidence, especially for walking in places he is not familiar with. With practice, it can also help him to walk in a faster, more normal way, with long, sure steps. This is because he can feel farther ahead of him with his stick than with his feet. The best age to start teaching a child to use a stick is probably about 6 or 7.

The stick should be thin and light, and tall enough so that it reaches half way between the child's waist and shoulders. The top of the cane can be curved or straight.

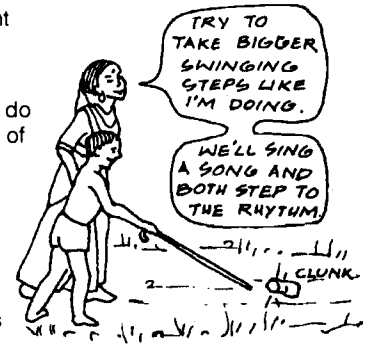


At first just give the child the stick and have him lightly touch the ground in front of him as he walks. His arm should be straight.

Play games letting him feel his way. But do not hurry him. Stop before he gets tired of it. At first, 5 or 10 minutes is enough.

After he gets used to the stick, walk beside him and encourage him to take smooth, even steps.

Have him swing the stick from side to side, and see if he can find things in his path.



After a time he can learn to use the stick better:

Move the stick from side to side, lightly touching the ground.

The width of the swing should be a little more than the width of his shoulders.

As the stick touches to one side, move the foot on the other side forward.

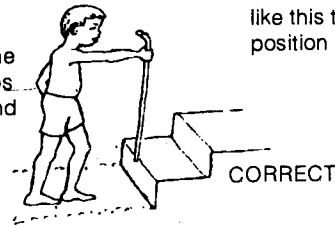


On a narrow path or rough ground, someone can lead the child by the stick.

Or the child can hold the person's elbow or wrist.

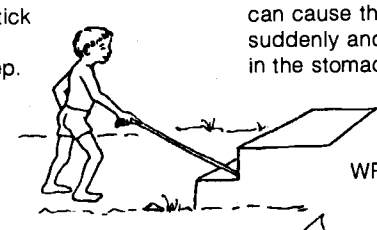


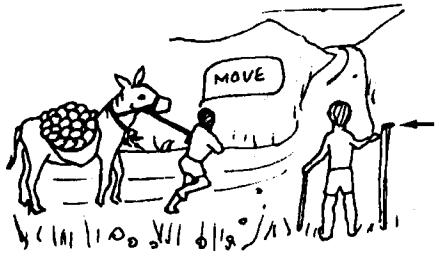
The child can learn to feel the height of steps and curbs, and then to climb them.



To go up steps, it is better to hold the stick like this to feel the position of each step.

Do not hold it like this. This can cause the cane to stop suddenly and hit the child in the stomach.





Teach the child to listen carefully before he crosses a path or road where cars or other traffic pass.

Putting posts or other markings where roads or paths cross can help the child find his way or know where to turn.

But whenever possible, **teach him to find his way using 'landmarks' that are already there.**



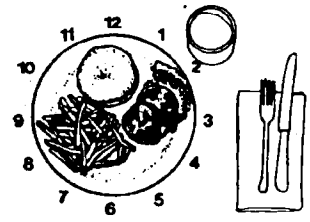
Sometimes putting a guide rope or rail can help the child find his way.

Helping the blind child to use his hands and to learn skills

Help the child who cannot see well to do all kinds of things with her hands, including daily care of herself: eating, dressing, bathing and toileting. Ideas for learning these skills are in Chapters 37 to 40.

At first you may need to help the child feel things by guiding his hands.

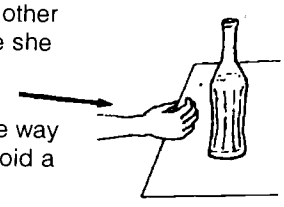






To help the child know where to look for the different foods on her plate, try to always put them in the same place. As the child gets older and learns to tell time, have her think of the plate or bowl as a clock. Tell her at what time each type of food is put on her plate. Here the glass of water is at 2 o'clock. Always put it at 2 o'clock.

Help the child learn to **put in the same place** glasses, cups, bottles and other things that can be easily spilled or broken. Teach her to remember where she puts things, and learn how to reach out for something and find it without knocking it over. **Reaching out with the back of the hand causes less spilling.** (This will take practice and there will be accidents, but that is the way she learns. Do not hand her everything or do everything for her, just to avoid a mess. Making a mess is part of learning.)





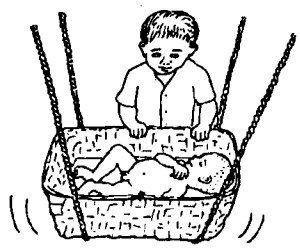
Help the child learn to recognize different shapes, sizes, and the 'feel of things' with her fingers. Let her play with toys and puzzles so that she learns to put different pieces together in a certain pattern or order. Ideas for toys and puzzles are on pages 562 to 573.

Teach the child about things he must be careful with or keep a distance from, to not get hurt; things such as fire, hot pans and dishes, sharp knives, dogs and mules that might bite or kick, deep holes, wells, cliffs, deep ponds or rivers. Do not just tell him "No!". Help him to understand the danger..



CAUTION: **Whenever possible, keep dangerous things out of reach or put fences around them, and take other precautions to protect the child-especially until he is old to be careful.**

Give the child **opportunities to begin to help** in different ways around the house. This will both increase her skills and give her a sense of being part of the life and action of the family.



Abdul helps rock his baby brother.



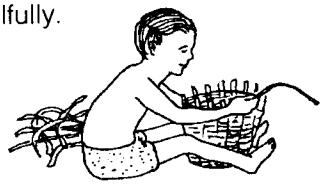
Rani's mother teaches her how to cook by guiding her hand and explaining each step.

When the child has learned to handle bigger things fairly well, help her learn to feel and handle smaller things. For example:

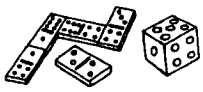
She can help sister pick the little stones and bits of dirt out of the rice.



If someone takes the time to teach him, a child can begin to help in a lot of things around the home, and also in village crafts. Weaving of mats, rugs, clothing, and baskets are things many blind children can learn to do well, and it helps them learn to use their hands skillfully.



Also, look for games and toys that help the child develop her ability to feel fine details and small shapes with her fingers.



For example, you can make dominos and dice out of wood. For the dots, hammer round-headed nails into the wood, so she can feel them. Or drill holes.

The child can learn to feel the dots with her fingertips. At the same time, she will begin to learn to count and use numbers.

You can start with 'giant' dominos and dice, and when her fingers learn to feel more skillfully, change to small ones. This will be a good preparation for doing many kinds of fine work and perhaps for learning to read braille.

SCHOOL

Blind children should have the same opportunity as other children to go to school. Ideas for how children in the community can help a blind child get to school, and help her in the classroom and with her studies are discussed in the CHILD-to-child activity on blindness.(see p.543).

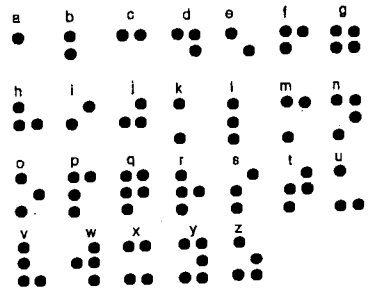
In most countries there are special schools that teach blind children to read and write '**braille**' Braille is a system of raised dots that represent letters and can be read with the fingertips. It was invented many years ago by a blind boy from France named Louis Braille.

Most village children do not learn braille in school. However, there are **many other ways** that they learn in school.

For the blind village schoolchild, one of the best aids for taking notes and reviewing lessons is a small **tape recorder**.. The family should try to save money to buy one. Or perhaps the school children can hold a raffle or collect money to buy one. other children can help record lessons from school books, and stories and information from other books.



THE BRAILLE ALPHABET





Louis Braille invented this dot alphabet at age 14. The dots are pressed into a thick paper from the opposite side with a pointed tool called a 'stylus'.

Braille has been developed in most Indian languages. For further information contact the National Association for the Blind and the National Institute for Visually Handicapped. Address at the end of the book

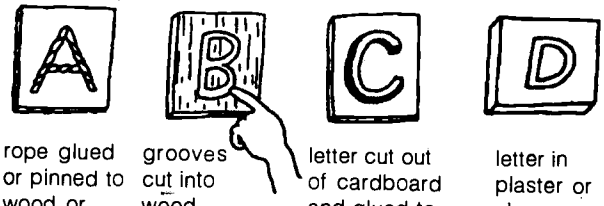
IMPORTANT: In order to keep up with her studies a blind child will need help. In school another child can read to her from her books. The child may also need extra help after school. An older brother or sister, or another schoolchild, can perhaps spend time teaching her at home.

Remember, **most 'blind' children have some useful vision. Encourage the child to use whatever sight she has.** If she can see big letters on the blackboard, write big and clear, and be sure she sits in the front. **Be sure the light is good, and that dark letters and things stand out against a light background.**

If she can see at all, to help her learn the letters, make them very **BIG**. Use white paper and dark ink.



To help the child learn the shape of letters by feel, you could make them in one of these ways.



rope glued or pinned to wood or cardboard.

grooves cut into wood

letter cut out of cardboard and glued to thick paper

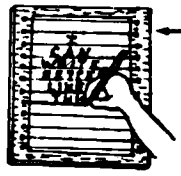
letter in plaster or clay.



In the schoolroom, a **pan with soft clay or mud** is helpful for learning to write and feel letters.



Children can practice writing outside in **sand, mud, or clay.**

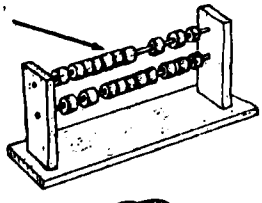


board with string stretched through holes

When the child begins to write, you can stretch string lines across the paper to help her write in straight lines. Or draw extra dark lines.

To help the child begin to count you can make a simple **'counting frame'**. The child can slide the beads or rings from one side to the other to count, add and subtract.

wood beads, or rings of bamboo

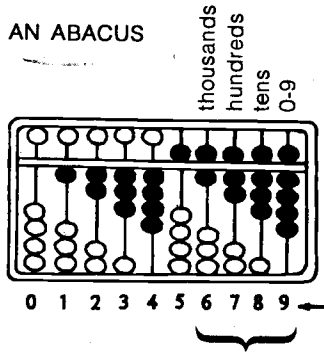


A pegboard like this can help a child learn numbers through touch– and help him learn to feel small differences in things.



When the child becomes more skilled with numbers, she can learn to use a special counting frame called an **'abacus'** which has beads on wires. The beads slide up and down to form numbers. With practice, a blind child can learn to add and subtract on the abacus as fast or faster than other children can do it on paper.

AN ABACUS



(All the beads are really the same color. Here we have made some black to make it clearer how to count).

The beads in the positions shown give these numbers.

These 4 wires now read 6789.
Notice that each bead above the center bar equals 5 times each bead birectly below it.

Work

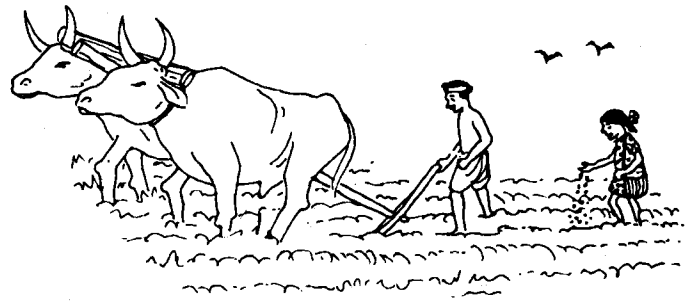
As a blind child grows up, or she can learn to do many different kinds of work. On page 620 in Chapter 35 we list many of the different kinds of work that disabled persons can do. Those types of work marked with a * have often been done by blind persons.

The village child who is blind should be given many opportunities to help with work around the home and with farm work. **The blind child should be invited and expected to help in a wide range of daily activities, just like the child who can** see. What starts out as play and imitation ends up as learning of useful skills.

A family that farms the land can begin to include a blind child in gardening and farming activities from an early age.



To get an understanding of the whole process of growing the family food, the child can start by planting seeds, watering them, caring for them as they grow, and finally harvesting, cooking and eating the product.



Later, the child can go with his father or mother to the fields and help with the planting. With his feet he can follow the furrows, or grooves made by the plow.

Try to involve the child with each aspect of housework and farm work. At first show her and guide her as much as is necessary. Then help less and less until finally the child can do the whole job alone.

Social Life

The blind child should have all the same opportunities in the community as other children do. Take her with you, and then send her, to the market, well, river,school and temple. Introduce her to the people you meet. Explain to them that she is an active little girl like any other, except that she cannot see. Ask them, when they see her, to make a point of speaking to her (since she cannot see them), of answering her questions, of helping her to find what she is looking for. Ask them not to do everything for her, but instead to help her figure out how to do more for herself. Little by little people will begin to realize that a blind child can do a lot more than they would ever have dreamed possible. And they will begin to respect and appreciate her. For the next blind child in the village, it will be easier.

Take the child to meetings, movies, puppet shows, and town events. Explain to her what she cannot see.

When children who are blind grow up, they can marry and have children. They can be as good parents as persons who see.

PREVENTION of blindness

The best way to prevent blindness is to **try to keep children well fed, clean and healthy**. During pregnancy, mothers also need to eat enough nutritious foods and to avoid medicines that might damage the baby. Specific steps to prevent some causes of blindness have already been discussed.

In brief, **steps to prevent child blindness include:***

- When pregnant, keep away from persons with German measles and other infectious diseases, avoid unsafe medicines, and try to get enough to eat.
- Protect the eyes of all newborn babies with tetracycline eye ointment or 1% silver nitrate drops at birth(see p.293).
- *Vaccinate* children against all the infectious diseases you can.
- Breast feed the baby, and continue to breast feed as long as possible.
- Good nutrition for mother and child–especially foods rich in vitamin A. Children often get diarrhea and then 'dry eyes' after they are taken off the breast. So, when the baby starts to eat other foods give him mashed papaya,mashed cassava leaves, or other foods with vitamin A, everyday.
- Keep the home and child clean. Build and use latrines, and keep them covered. Try to protect against flies. Wash hands with soap and water, especially before eating and after using the latrine(toilet).
- Keep the child's eyes clean. When they get infected or have pus, clean them often with a clean cloth that is wet with clean water, and see a health worker.
- Give children with measles vitamin A rich foods(or vitamin A capsules, see p.294) because danger of 'dry eyes' increases with measles.
- Treat all persons with signs of trachoma early. For treatment of different eye problems , see a health worker or get information from a book like ***Where There Is No Doctor***.
- Keep sharp and pointed objects, bullets, explosives, acids, and lye away from children and teach them about their dangers. Warn them about the danger of throwing closed bottles, cans, or bullets into the fire. Also warn them about local plants that can injure the eyes. Get good early treatment for any eye injury.
- Warn children about throwing rocks and sticks, or shooting slingshots and arrows toward other persons.
- Check babies and children for early signs of eye problems or difficulty seeing. Test how well they can see at 2 months of age and before they begin school.
- Organize children to test the sight of their younger brothers and sisters(see CHILD-to-child ,p.546).
- Help everybody understand that **most blindness in children can be prevented**. Teach people what they can do.



- For special precautions to protect the eyes of persons who have a loss of feeling in their eyes, see Chapter 26 on Leprosy, p.264.

NOTES

CHAPTER 31

Deafness and Communication

Different children have different amounts of hearing loss

A few children are **completely deaf**; they do not hear at all. Parents often notice early that their child cannot hear, because she does not turn her head or respond, even to loud sounds.



The child who is completely deaf does not respond even to very loud noises. (But he may notice movements or vibrations caused by sudden loud noises. For example, clapping behind the child's head may move the air at his neck and cause the child to turn.)

Much more often, children are **partly deaf**. A child may show surprise or turn her head to a loud noise, but not to softer noises. She may respond to a low pitched sound like thunder, a drum, or a cow's 'moo', but not to high-pitched sound like a whistle or a rooster crowing. Or (less commonly) a child may respond to high pitched sounds but not low ones.

Some children who are partly deaf hear a little when people speak to them. They may slowly learn to recognize and respond to some words. But many words they do not hear clearly enough to understand. They are slow to begin to speak. Often they do not speak clearly, mix up certain sounds, or seem to 'talk through their nose'. Unfortunately, sometimes parents, other children and teachers do not realize that the child has difficulty hearing. They may treat her as if she is *mentally* slow or 'dumb'. This only increases the child's problems.



The child who is only partly deaf hears some sounds, but may not hear clearly enough to tell the difference between certain sounds or words. Families are often slow to recognize that these children have difficulty hearing.

Problems that may result

For most growing children, hearing and language are very important for getting to know, understand and relate to the people and things around them.

COMMUNICATION is the way in which we understand what is said to us and the way we say or **express** to other people our thoughts, needs, and feelings. People who can hear, communicate mostly through **speech**.

For children with a hearing loss, the biggest problem is **learning to communicate**. Because they cannot hear words clearly, it is much more difficult for her to learn to speak. So she has trouble both understanding what people want, and telling them what she wants. This can lead to frequent disappointments and misunderstandings, both for the child and others. It is no surprise, then, that children with hearing loss sometimes are slow in learning **to relate to other people**, feel **lonely or forgotten**, or develop **'behavior problems'**.

The exchange of ideas and information through some form of communication is important for the development of any child's mind. Most deaf children are just as intelligent as other children. But for their mental ability to develop fully, they need to learn to communicate well from an early age.

How deafness affects a child depends on:

1. **when the child becomes deaf.** For a child who is born deaf or becomes deaf before he begins to speak, learning to speak or 'read lips' will be far more difficult than for a child who loses his hearing after he has begun to speak.
2. **how much the child still hears.** The better the child hears, the more chance he has of learning to speak, understand speech and 'read lips'.
3. **other disabilities.** Some deaf children also have other problems. A child who is **mentally retarded**, blind, or **'multiply disabled'** will have a harder time learning to communicate than a child who is only deaf. (See "Causes of Deafness") **In 3 out of 10 children the cause for deafness is not known even in the best clinics in the world.**
4. **How soon the problem is recognized..**
5. **How well the child is accepted and how early he is helped to learn to communicate.**
6. **The system of communication that is taught** to the child. ('oral' or 'total', see p.317)

How does *deafness* affect a person

	Partial loss	Profound loss
Basic Physical growth	normal	normal
Speech	unclear speech.	no speech
Communication	Combination of gestures and speech usually.	sign language if taught or gestural system (using gestures)
Social Skills	Generally manage to establish rapport, specially in familial environment and with known people.	more prone to isolation by the society at large.
Education	Can manage well in an integrated school and sometimes even in normal schools but with a lot of hard work.	Cannot attend normal school, must go to a special school if possible.
Language	If the environment is bi/multilingual then language learning can become difficult. It is advisable to restrict to one language only.	no spoken language
Employment	Very often secure jobs on their own merit and generally do well.	Once they get employment, as a rule they are sincere workers.
Matrimony and children	Can marry someone with or without hearing loss and may have normal children.	Can marry someone with or without hearing loss and may have normal children.

CAUSES OF DEAFNESS

Deafness is **not** caused because the parents did something wrong or because they are being punished.

Common causes before a baby is born:

- **Hereditary** Deafness occurs due to problems existing in the chromosomes (or tiny chemical messages that determine what a child will be like inheritance) of hearing parents or genetically deaf parents. Fifty percent of all deaf children are hereditary deaf. There is as yet no chromosomal test for detecting the abnormal gene that causes deafness.
- **Rubella:** This is commonly referred to as German measles. This mild infection of the pregnant mother causes deafness, brain damage, heart and kidney problems in the unborn baby. This is diagnosable with repeated blood tests before and after birth.
- **Iodine:** Lack of iodine in mother's diet (common in areas where many people have goitre) may show signs of mental retardation or cretinism. (see p.342).
- **Not all babies** are born deaf with Rubella.
- **Rh factor:** When the mother is Rh negative and if the baby is Rh positive then problems occur during pregnancy and immediately after birth. **This is diagnosable and proper management is available in most of the hospitals in India.** Child often has other disabilities also, (see p.345)
- **Medications:** Medicines damage the ears of the unborn child but do not affect the hearing of the mother. Some of these medicines are **Streptomycin, Gentamycin and Kanamycin injections, Frusemide etc. Diabetes, Kidney diseases and liver diseases** in the pregnant mother also lead to babies having deafness. Similar risk exist even when these medicines are taken post-natally.

During the birth of the baby:

- **Hypoxia:** Difficult and prolonged labor leading to reduced oxygen for the baby leads to deafness and additional disabilities like cerebral palsy and mental retardation.
- **Pre-maturity:** (Babies being born early and small). Their chances for survival depends on their weight and weeks of development. Many premature babies who never survived earlier, are surviving today, but with disabilities like deafness. (The baby's tissue is very susceptible to any lack of oxygen).

After Birth:

- **Hereditary:** Chromosomal disorders which are familial in nature causes deafness in children at anytime under the age of ten and progress rapidly to a profound level. These children are often born with normal hearing.
- **Infections:** They form a large group, with infections of the meninges (explain) and brain causing the most damage. Viral and other bacterial infections also cause deafness. Chronic ear infections that are not attended to for long periods of time can lead to deafness.

In 3 out of 10 children the cause for deafness is not known even in the best clinics in the world.

Importance of early recognition of deafness

During the first years of life, a child's mind is like a sponge; it learns language very quickly. If a child's hearing problem is not recognised early and effective help is not provided the best years for learning communication skills may be lost(age 0 to 7). The earlier special training begins, the more a child can learn to communicate. Parents should **watch carefully for signs that show if a baby hears or not.**

Identifying children with hearing difficulties

0-3 months
Newborn is not startled in response to a loud clap within 3 feet.

3-6 months
Baby does not search for source of sound with eyes.
Does not respond to cooing and babbling of parents.

6-10 month:
Does not respond to name, a ringing bell or to a voice.
Does not understand simple phrases like 'no-no' or 'bye-bye'.

10-15 month:
Child cannot point to objects or people.
Does not initiate simple sounds and words.
Does not respond to name or speaker unless he sees the speaker.
Shows no interest to sound (radio).

15-18 months
Does not follow simple directions.

18 months to 3 1/2 years:
No noticeable increase in vocabulary.
Child used gestures almost exclusively to establish needs and desires as opposed to speaking.
Does not enjoy listening to stories.
Has history of earaches or ear infections.
Appears disobedient.

3 1/2 to 5 years:
Child cannot locate source of sound.
Cannot understand and use simple words such as **'go, me, in, big, etc.'**
Cannot give connected account of some recent experience.
Cannot carry out two simple directions in a row.
Cannot carry on a simple conversation.
Child's speech is difficult to understand.

School going child:
Has trouble paying attention.
Does not answer when called.
Gets confused about directions or does not understand at all.
Often gives the wrong answers to questions.
Appears slow and does not do well in school.
Has a confused expression when directions or questions are being given.
Has poor speech, substitutes sounds, omits sounds or has poor voice quality.
Avoids people, plays alone, seems resentful or annoyed.
Gets tired early in the day, seems restless or strained.
Turns one side of his head towards sounds, indicating hearing loss in ear.
Suffers from frequent colds and earaches.

(Childhood Disability Information Kit, Hearing and Speech, Unicef, Kathmandu, Nepal).

Unless a child is given a lot of understanding and help learning to communicate from an early age, deafness can be one of the most difficult, lonely, and misunderstood disabilities. The following 2 stories will help show the difference that it can make to recognize a hearing problem early and provide the extra help that the child needs.

ANUJ

Although Anuj was born with a severe hearing loss, his parents did not realize this until he was 4 years old. For a long time, they thought he was just slow. Or stubborn.

Until he was one year old, Anuj seemed to be doing fairly well. He began to walk and play with things. Then his sister, Lila was born. Lila smiled and laughed more than Anuj when their mother talked or sang to her. So their mother talked and sang to Lila more.

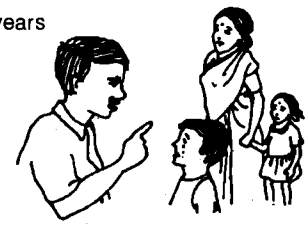
By the time Lila was 1. she was already beginning to say a few words, Anuj has not yet begun to speak, "Are you sure you can hear?
" a neighbor asked one day. "Oh yes," said his mother. She called his name loudly and Anuj turned his head.

When he was 3, Anuj could only say 2 or 3 words. Lila, at age 2, now spoke more than 200 words. She asked for things, sang simple songs and played happily with other children. Anuj was more moody. Mostly he played by himself. When he played with other children it often ended in fighting - or crying.

Lila behaved better than Anuj. Usually, when her mother told her not to do something and why, she understood and obeyed. Often, to make Anuj obey,, his mother would slap him.

One time in the village market Lila asked for a banana and her mother bought her one. A moment later, Anuj quietly picked up a mango and began to eat it. His mother slapped him. Anuj threw himself on the ground and began to kick and scream.

When Anuj's father heard what had happened in the market, he looked angrily at Anuj and said,"When will you learn to ask for things? You're 4 years old and still don't even try to talk. Are you stupid, or just lazy?"



Anuj just looked at his father. Tears rolled down his cheeks. He could not understand what his father said. But he understood the angry look. His father softened and took him in his arms.

Anuj's behavior got worse and worse. At age 4 his mother took him to a health worker, who tested Anuj and found that he was deaf. Now Anuj's parents are trying to make up for lost time. They try to speak to him clearly and slowly, in good light, and to use some signs and gestures with their hands to help him understand. Anuj seems a little happier and speaks a few more words. But he still has a lot of trouble saying what he wants.

SUMAN

When Suman was 10 months old, her 7 year old brother, Sunil, learned about testing for deafness as part of the CHILD-to child program at school (see p.544). So he tested his baby sister. When he stood behind her and called her name or rang a bell, she did not turn or even blink. Only when he hit a pan hard did she show surprise. He told his parents he thought Suman did not hear well. They took Suman to a small rehabilitation center. A worker there tested Suman and agreed she had a severe hearing loss.

The village worker explained what the family could do to help Suman develop and learn to communicate. He gave them many drawings of hands held to make 'signs' for common words.

"Every time you speak, make 'signs' with your hands to show what you mean. Include all the signs and gestures that people already use in your village. Teach all the children to use them too. Make a game out of it. At first Suman won't understand. But she'll watch and learn in time she'll begin to use signs herself."

"If she gets used to signs, won't that keep her from learning to speak?" asked her father.

"No", said the worker, "Not if you always speak the words at the same time. The signs will help her understand the words, and she may even learn to speak earlier. But it takes years to learn to speak with 'lip reading'. First, she needs to learn to use signs to say what she wants and to develop her mind."

Suman's family began using signs as they spoke to each other. Months passed, and still Suman did not begin to speak or to make signs. But now she was watching more closely.

By age 3, Suman began to make signs. By age 4 she could say and understand many things with signs-even lip read a few words, like 'Yes', 'No', and `Sunil'. By age 5 she had only learned to 'lip read' a few words. But with signs she could say over 1000 words and many simple sentences.



Suman was happy and active. She liked to color pictures and play guessing games. Sunil began to teach her how to draw letters. One day she asked Sanjay when she could go to school.

WHERE CAN YOU GO FOR HELP ?

A child who does not hear needs all the help he can get. Where you can look for help depends on where you live and what resources are available in your community and in your country. Here are some possibilities.

In the rural areas people can go to a health care centre, to the Anganwadi worker or to centres being run by voluntary organisations if they are nearby. In the urban areas they must take the child to a Speech and Hearing clinic, ENT unit of any hospital or to special institutions for the handicapped.

- **Local deaf persons as teachers:** Even a small village usually has some persons who have been deaf a long time. Probably they will have learned to communicate through signs and gestures. If you ask some of them to become the friends and teachers of a deaf child, and advisers to the family, often they will be glad to do so. They may remember the difficulties and loneliness of their own childhood and want to help provide the understanding and learning opportunities that the deaf child needs.

  Deaf persons can be especially helpful if they have learned the 'national sign language' and can communicate fully with other deaf persons. If there is no such person in your village, but there is in a neighboring town, perhaps the child can visit that person, or a group of deaf persons.



Deaf persons who have learned to communicate well are often the best teachers of a deaf child and his family.

- **Other families with deaf children:** If several families with a deaf child can come together ,share experiences and learn as a group, this can be a big help. The younger deaf children can learn from older ones, or from deaf adults. Together they can develop a form of communication so that all the children and their families can understand each other. **(example of a self help group).**

- **The National Association of the Deaf:** (or other group **run by the deaf**) India, like most countries has associations of deaf persons. These can give you information about the national sign language and perhaps send books for learning it. They can tell you about training programs for the deaf (government and private) and can advise which are the best. They may even provide brief training in basic communication skills to a local health worker, teacher, family member, or disabled child- with the understanding that he or she then teach others.

  In the rural areas people can go to a health care centre, to the Anganwadi worker or to centres being run by voluntary organisations if they are nearby. In the urban areas they must take the child to a Speech and Hearing clinic, ENT (ear, nose and throat) unit of any hospital or to special institutions for the handicapped.

- **'Special education' programs for the deaf:** There are schools in our country where deaf children can live and receive special training. Some of these are good and some are not. Good programs try different methods of communication with each child and then focus on what will probably work best for that child in his community. But learning

Two questions parents often ask.

1. **Who will check the child's ears for wax, infections etc, and confirm whether the child's ear is normal or not?**

   Answer: An ENT (Ear, Nose Throat) doctor will check them.

2. **Who will check the ears to establish:**
   a. If there is hearing loss
   b. How much loss is there
   c. What is the type of loss
   d. Fitting of the hearing aid.
   e. Further rehabilitation of the child in speech and hearing.

Answer: A Speech Pathologist and Audiologist (Speech & hearing specialists) and sometimes also health workers who have been trained by speech and hearing specialists and work under their supervision will answer these questions.

Take your child to an **Audiologist** for testing his hearing and fitting the hearing aid if required. Take your child to the **speech Pathologist** who will teach your child to communicate and speak.

Deciding what to do for a deaf child

All children with hearing loss are not the same. All need love, understanding, and help learning to communicate. But **different children need different kinds of help. , to communicate in whatever way works best for them. We must adapt our methods to the needs of the particular child and to the realities of the community where he lives.**

- A parent should get a complete assessment of the hearing impairment and to know for certain that there are no additional disabilities. It is necessary to know for sure whether the child has one disability or more, as management, goals and expectations change with it.

  If as a parent, teacher or a family member you have felt any reason to suspect that the child may have a hearing problem get his ears checked. Find out from the Audiologist the amount of loss and the type of loss.

- Hearing loss caused by wax or ear infections can be cured with medications. An inner ear loss cannot be cured with medication. The only cure is a **hearing aid with auditory training** which means that the child has to be trained to become aware of sounds, discriminate different sounds and also receive speech therapy.

  Note: Cochlear Implant surgery (Cochlear- sensory part) of the ear can be done at a huge cost, only if the child cannot be helped with a hearing aid and has hearing loss in both ears.

- Parents should attempt to procure the best hearing aids for their child. The hearing aids should be easily servicable and repairable without having to send it far. Any other accessory necessary for the deaf child should also be in the knowledge of the parents. Like batteries, lights for the door bell etc.

  REMEMBER that fitting a hearing aid is not a cure as hearing aid is only an amplification device like loud speakers. Also the hearing aid must be fitted by an audiologist.

- For a child who has not heard anything from birth, hears only noise when hearing aid is fitted. But with the help of auditory training and speech therapy, he learns to associate meaning to these sounds.

This training to pick out speech sounds, meaningful sounds from noises he hears and later learning to say the sounds and communicating using all possible means is given by a Speech Pathologist and Audiologist.

The training a child needs to get depends on the age, degree of loss, type of loss, age of detection etc.

- Besides receiving speech training all possible efforts must be made to admit the child in school, a normal, integrated or a special school for the deaf depending on the degree of loss. Children learn well when they interact with other children. Deaf children need the company of deaf and other children and should have the opportunity to socialize and interact with them. This is as important as wearing the hearing aids and learning to speak.

Along with education some form of vocational training must also be given. (for ideas on the kinds of work disabled children can do, see chapter on work).

- Parents should get to know more about this disability or disabilities by reading books or meeting parents of other deaf children near their locality. Decisions have to be taken by the parents regarding the mode of communication for their deaf child, method of education etc. The more their information the better their support to their child.

Parents need a lot of guidance and information to be able to help their own child. It is only with this help and guidance that parents can best help their child. If the professionals are close by or easily approachable then assistance may be on daily basis. If they are far away then may be once a week, once a month or twice a year, depending on how easy it is for the deaf child and the family to commute to and from the professional. **A great deal of professional guidance can be put into practice by the parent or the health worker if it is on a regular basis even though it may be less frequent.**

Note: Some children who hear perfectly well do not develop the ability to speak. Some children with cerebral palsy do not control their mouth or tongue movement well enough to speak. Other children are mentally retarded and may be very late in learning to speak, or never learn. Other children are intelligent in many ways, but for some reason cannot speak. For all of these children, we need to look for ways to help them communicate as best they can. They will not require hearing aids and they should not be managed like a deaf child.

HELPING A DEAF CHILD TO HEAR BETTER

Some children can sometimes be helped to hear better.

- Have the child's hearing and ears examined by a specialist. A few children are born with a closed ear tube or other **defect in the structure of the ear**. Rarely these problems can be corrected by **surgery** and the children can hear better.

- Children who have hearing loss because of **ear infections** may begin to hear better if the ear infections are treated early and steps are taken to prevent more infections. (See p.331)

Auditory Training

Young children who do not hear well can sometimes be helped to **listen more carefully**, and to learn the difference between sounds. Make different sounds and encourage the child to take notice. When a donkey brays or a baby cries say clearly and loudly, "Listen to the donkey," or "What was it?" If the child answers or points in the right direction, praise him.



Have the child make different sounds – hitting pans, drumming, ringing bells, and so on. See if he can move or dance to the beat of music or drums.

Talk a lot to the child. And sing to her. Tell her the name of different parts of her body and other things. Ask her to touch or point to them. Praise her when she does.



Experiment to find out how near the child's ear you need to be, and how loud you have to speak, to get the child's attention or for him to repeat the sounds you make. Then try to speak near and loud enough. Speak clearly, but **do not shout.**

Auditory training must be given to help the child hear better. This is a long term training of the child to help him attend to sounds.

Material needed to produce different types of sounds. You can use flute, drum, rattle, squeakers, Ghungurus (bells) environmental sounds such as those made by a dog, cat, train, kitchen sounds etc.; speech sounds such as the names, specific sounds such as PA, LA, CHA, etc.; 5 or 6 similar looking objects such as color pencil, marbles, pens etc.

Method

1) Place the child in a room free from any outside noise.
2) Make him sit comfortably placing similar looking objects on one side, (left) hand.
3) Sit opposite him, pick up one of the objects, say, a pencils and place it near your ear and prompt him to use the same.
4) Now make a sound with any of the objects, the drum for example.
5) Immediately on hearing the sound, place the pencil on the right hand side and pick up another pencil from the left and prompt him to do the same.
6) Explain verbally and also with gestures that when he hears the sound he must put down the object.
7) Repeat many times using different sounds.
8) Once the child seems to be responding correctly to sound, remove the object so that **now he cannot see you making sound but only hears the sound you make.**
9) Repeat all the steps now, while making sound he can only hear and not see the sound being made.
10) Repeat this game daily, many times a day.

Make different sounds like TOY SOUNDS, ENVIRONMENTAL SOUNDS AND SPEECH SOUNDS.

Hearing Aids

Some children can hear better with aids that make sounds louder. A 'hearing aid; allows the child to hear sounds fairly well, and can make a big difference in learning to listen and speak. For other children, an aid makes them more aware of sounds (which helps) but does not help them to tell the difference between words.There is no age for fitting of hearing aid. It should be fitted as early as possible. If it appears that a child will benefit from a hearing aid then he must begin using it as early as age 1 or 2.

The simplest aid is a **hand cupped** behind the ear.



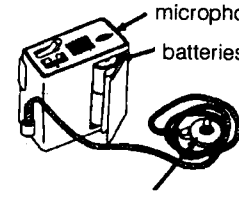
Better is an **'ear trumpet'**. You can make one out of cardboard or tin.



Better still (for some children) is **'hearing aid' with batteries.**

But usually these are expensive. For best results, it should be fitted by Audiologist after the child's hearing has been carefully tested.





Piece that fits into ear (best if molded to fit the specific child). In a growing child it will need to be changed often.

The model of hearing aid as shown in the picture is still used in rural settings as it is cheaper to buy and maintain. But other smaller hearing aids like BTE (Behind The Ear), aids that can be fixed onto spectacles, called Spectacles aids and those that can be fitted into the ear (canal) are also readily available.

The best hearing aid for a deaf child is not the most expensive, the most sophisticated or those made in a far off place but one with which the **child hears best.** It is therefore best to buy the hearing aid only after checking if the child hears with that particular model of hearing.

India has a well established hearing aid industry which has been manufacturing and assembling hearing aids for the last 30 years or more. There are two main types of hearing aids available for children with deafness.

1. Body worn or Pocket Hearing aids.
2. Behind the ear hearing aids. (B.T.E.)

The approximate cost of hearing aids and batteries

Body level	-	Rs. 750 to Rs. 2600
Behind The Ear	-	Rs. 1400 to Rs. 7200
In the ear	-	Rs. 6500
Spectale aids	-	Rs. 8000
Batteries	-	Rs. 15 to Rs. 25 per cell

The ears of the child have to be carefully examined by a doctor. **All infections like fungus, wax and discharge** have to be medically managed before a hearing aid is fitted. **Hearing aid if fitted in a ear with infection will increase the infections, which in turn will increase deafness.** Even a small thing like removal of wax would make a great difference.

When buying or receiving a hearing aid the parent should take time to learn how to take care of it. It is extremely important to learn to know if the hearing aid is working properly every morning by a simple test learnt from the professionals. The hearing aid can only be fitted on to the ears with the help of **ear molds.** These molds are made of denture material and need to be made for each child after taking an impression of her ears. It is necessary to get a pair of ear molds made when one purchases the hearing aids. The ear molds may have to be replaced twice a year in babies and once in two years in older children. **The hearing aid is only as good as the ear mold.** The rubber or plastic **ear tips are not advised** for use with children with deafness.

Maintenance of hearing aids

Parents of small children must ensure that the aid does not fall and water does not get into the aid. The attachment whether a mold or ear tip must be regularly cleaned to make sure that the sound passage is not blocked. For servicing it should be taken back to the place from where it was purchased, if possible. If one is living in a coastal area like Kerala, West Bengal or Maharashtra, or in an area where there are consistent heavy rains like Assam, Maharashtra, Kerala and Tamil Nadu then the hearing aids have to be stored in a special box at night which will de-humidify' (remove all moisture or dampness) it at night. This can be got from the dealers or manufacturers of hearing aids.

Can you get hearing aids free or at subsidized rates?

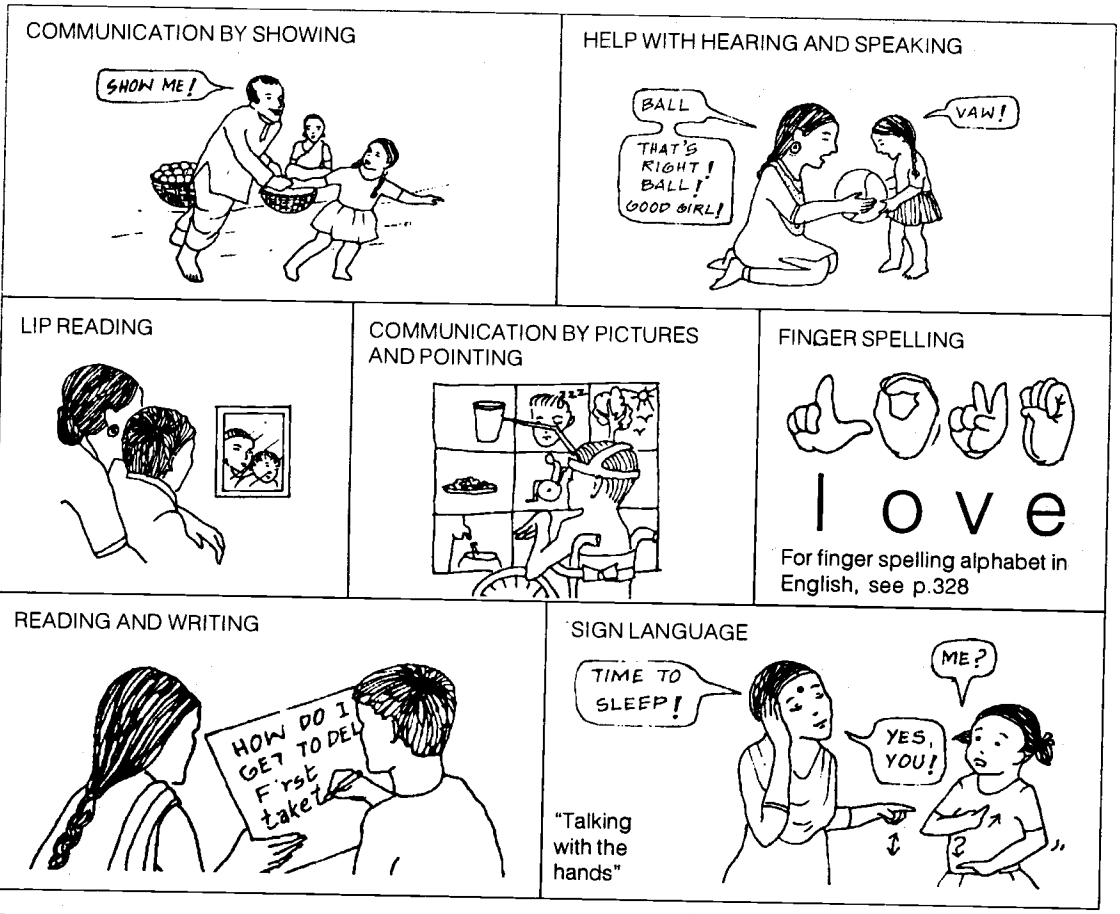
Yes. The government gives hearing aids either free or subsidized at the ENT departments of government hospitals when you produce your income certificate, certified by the Tehsildar of your village. Some voluntary organisations like the Rotary, Lion, All India Federation for the Deaf, and Mangalam are some of the agencies that give free hearing aids.

Batteries for the hearing aids have to be always kept in the house, ready for use to avoid any disruption, even if there is a sudden short supply in the market. There are two types of hearing aid batteries. The R6 or what is referred to as "Penlight-cell" and the R44 called "button cell". The R6 battery lasts longer and is cheaper that R44 cell. When deciding to buy the hearing aids the monthly expenditure on batteries should be taken into account. Anyone donating hearing aids may be asked to supply the required batteries for a whole year, if possible. Most of the batteries have a life of 15 to 20 days when used for the whole day. Battery chargers are also available.

Important: Many parents often do not use hearing aids received from such sources or have one hearing aids tucked away unused in their cupboard. The reason they give for this is that **the child did not hear with them.** Unless proper matched hearing aids are given this kind of assistance will be like giving the child a wrong sized shoe to wear.
It will never be worn.

CAUTION: Simply wearing hearing aids is not enough. It must be immediately followed with **auditory training and speech therapy.** If you get your child a hearing aid, be sure to ask for instructions on keeping it clean, dry and working well. Be sure you have a supply of extra batteries and know how and where to get them. **Remember that a hearing aid is only a loud speaker not a cure.**

DIFFERENT WAYS TO HELP A CHILD COMMUNICATE



COMMUNICATION:

Children who have hearing problems can be helped to communicate in many different ways . Oral speech, lip reading, gesture, sign language, finger spelling, drawing, reading and writing, total communication.

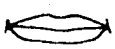
Oral Communication

Along with auditory training, the child with hearing loss must be taught to speak because he cannot acquire speech like a normal hearing child in the normal course of time.

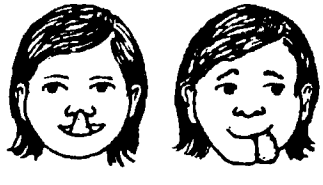
Helping the child learn to make sounds and speak

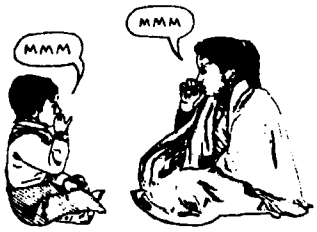
1. If the child hears at all, encourage her to **notice and listen to different sounds**, (as discussed on p. 313 to 315.)

2. Play games and do exercises to help her learn to **use her mouth, tongue, and lips** (see p. 384 and p. 385). Have her press her lips together as if saying

"mmm,"  make a circle like 'O'  and stretch her mouth and smile as if saying "eee" 

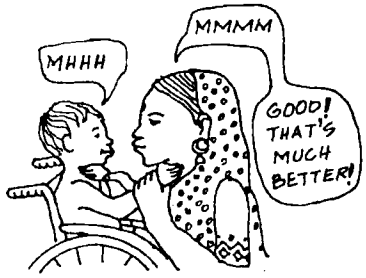
See if she can touch her nose, her chin, and her cheeks with her tongue. Have her blow soap bubbles, or blow out candles. Give her foods to chew and suck.





3. Encourage the child to **begin to make sounds**. 'Mmm' is good to start with because it is easy to make. If necessary, show the child how he can hold his lips together to make it. Sit close to him so he can see (and hear?) and copy you. Other sounds that are usually easy to learn are 'ah','ay','ee','aw', 'o','p','b','t',and 'd' (Keep more diificult sounds like 'v', 'w','j','s', 'n', 'r' and 'z' for later).

4. If the child uses his mouth and lips, but not his voice have him feel the 'buzz' or vibration in your throat when you make different sounds. To get the 'feel' of different words, you can place his hands on your cheeks, lips, throat and chest. Then have the child feel his own throat, as he tries to copy you.



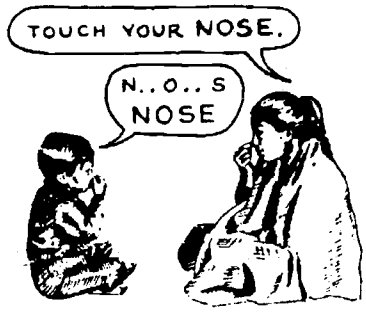


5. Also have the child feel and compare the movement of the air in front of your mouth and his mouth with sounds like'ha', ,'ho','m','p', 'b', and 'f'.

In the same way, have him feel the air move when he 'blows
his nose' with his mouth closed. Using this, try to teach sounds like'n' and 'l'

6. Begin to teach the child words using the sounds he is learning. First separate the word into different sounds. To say "Ma," first get the child to say"m" with the lips closed. Then "ah" with the mouth open. Then say the word "mah" and have him try to copy you.

7. As the child learns words, teach him what they mean, and have him use them. For example to teach the child 'nose' have him make the sounds 'n','o' and 's'. Then have him put them together. Ask the child to touch his nose as he says the word. Have him copy you. Praise him and make it a game.



8. Little by little, help the child learn more words and practice using them through games and daily activities. Have her learn her own name and the names of family and friends. Build up a word list as explained on p.330. But do not try to go too fast. Take time to help her say a few words fairly clearly before going on to the next.

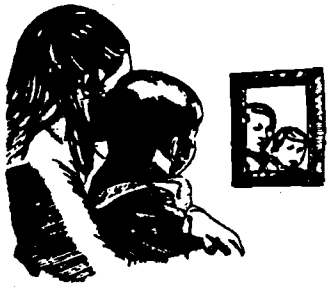
Lip reading

Children with a lot of hearing loss often depend partly on lip reading to understand what people are saying. But lip reading is not easy to learn. Do not try to hurry the child or she(and you) can easily get discouraged.

Sit in front of the child in good light, and show him something, for example, a ball. Say "ball", moving your lips clearly and speaking slowly. Let the child see your lips move and watch your face. Repeat the same word many times.



Then have the child try to imitate you, and feel his own lips as he does.



Next sit with the child in front of a mirror, so that he can see both of your faces. Say the word "ball" and then have him copy you, watching both of your lips and faces in the mirror.

In this way teach him different words. Start with words where the lips move a lot, and that are easy to tell apart. Pick words that you can use often with him in games and daily activities. When you speak to him, make sure he is watching your face and mouth. Use hand signs when he cannot understand a word. But use the sign ***after*** speaking the word, not at the same time. He cannot watch both at once.



Be sure the child is watching your lips.

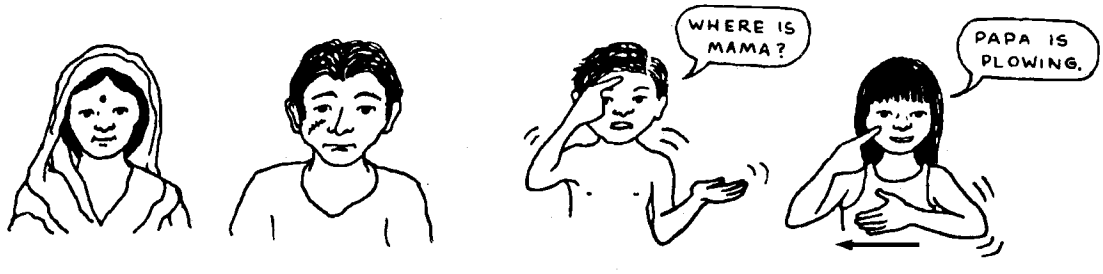
You can play games with the child together with children who hear, using'mime' – that is,acting things out and saying words with the mouth, without making sounds.

Unfortunately, some sounds and words look exactly the same on the lips – the sounds 'k','g', and 'h', look the same,'P', 'b' and 'm' look almost the same. 'T','d','s', and 'z' look the same. And so do 'ch' and 'j'. To help the child tell similar words apart, use hand signs or give him small 'clues' like touching parts of the body, clothes, or food. For example :

If mama wears a dot on her forehead,

and papa has a scar on one cheek,

when anyone at home speaks of them they can also give the 'magic sign'



SIGN LANGUAGE

The word 'sign language' means a language which uses expressions and gestures. It is a complete language by itself. This system of communication is used to meet the special needs of people with hearing impairments all over the world. Through the sign language these people are able to communicate their emotions and ideas to others. As with any language spoken or otherwise they have different symbols and certain grammatical norms. These symbols require body language and facial expressions to convey meaning. The sign language uses hands, face, even arms, body posture and space around the body for its communication.

When we speak we use vocal words using the tongue, mouth and lips and the receiver uses the ears to hear (oral-aural). But in a sign language the speaker uses gestures and facial expressions to convey the meaning and the receiver uses the eye to understand the meaning of what is being communicated (gestural - visual).

All over the world teachers have worked hard to make English easier to learn for children with hearing impairments. Codes have been created along with local existing codes and put into the order of the English language or an Indian language. Some of the codes have been taken from the American Sign language. The sign language is thus an invention of a
language and is similar or close to the spoken language.

The sign language uses both manual and non-manual aspects of communication.

In most villages and communities people use and understand many gestures or signs made with their hands. Most of these signs are 'common sense', or look something like the things they represent. for example :

"Here's the Church "



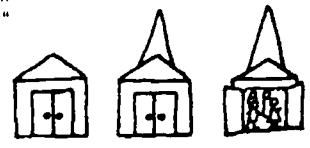
"And here's the steeple"



"Open the doors"

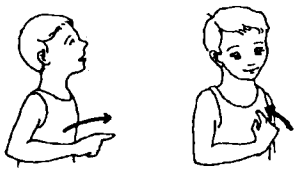


"And see all the people "

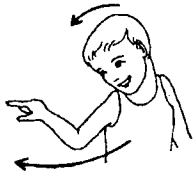


When a family has a deaf child, they begin to use the local signs and also to invent new ones of their own. For example, at a village rehabilitation center in Mexico, a family arrived on muleback with their 6 year old deaf son. The boy got nervous and wanted to go home. So he pulled on his father's shirt sleeve and made these sounds and signs

YOU and ME



LET's GO (home)



RIDING THE MULE



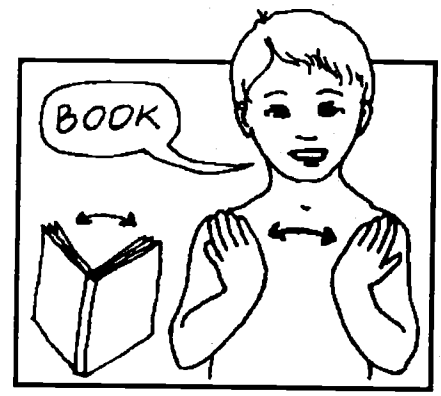
PLEASE!



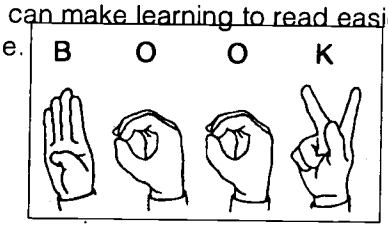
The family had begun to figure out his own sign language, without having been taught it. The boy himself had made up the sign for 'RIDING the MULE'

The sign language that families develop with their deaf children is usually not very complete. Communicating is often still difficult. However, people have joined together to create sign languages which are much more complete. There are hundreds of different sign languages, but there are 3 main types:

- **The National and regional sign languages** In nearly all countries, deaf people have created their own sign languages in which they can learn to communicate as well and nearly as fast as hearing people. Different hand signs represent different things, actions and ideas. The structure (grammar) of these languages is different from the spoken language, and therefore is difficult for hearing people to learn. These languages are preferred by people who were born deaf. Example is the American Sign Language (ASL) which is also used extensively in India.

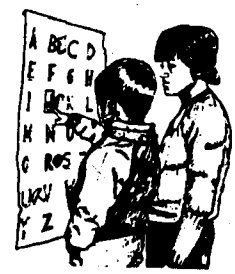


- **Sign languages based on spoken languages.** These languages have the same organization and grammar as the local spoken language. They are easier for hearing persons to learn and for persons who became deaf after they learned to speak. Sometimes they use the first letter(finger spelling) of a word as part of the sign. This is harder for children to learn who cannot read, but can make learning to read easier and more fun. Examples are English Sign Language.



- **Finger spelling** Each word is spelled out with hand signs that represent the letters of the local alphabet. This method of 'writing in the air' is slow but exact. It is easier for persons to learn who can already read and write.

Many deaf persons combine these 3 systems. With other deaf persons they use mostly the first, with hearing persons or a 'translator' they use mostly the second, and finger spell difficult words. When 'talking' to someone who does not know sign language, they can write down what they need to say–or use a letterboard.



Indian sign language

Mainly two types of finger spelling are used in India – using **one hand** as in the American system or **both hands** as in the British system. The Ali Yavar Jung National Institute for Hearing Handicapped (Bombay) has developed the Indian Sign Language based on the English alphabet. **The Indian Manual Alphabet system** called Karapallavi was originally adapted and developed for the Marathi, Hindi and Gujarati speech sounds in 1978. Later changes/modification were made to encompass 10 of the major Indian languages. Described here is based on the American one hand system. This has been translated / adapted to suit the needs of all Indian languages. This manual alphabet can be tried all over the country by deaf people as well as the professionals working for the deaf. This system encourages the uniformity in the use of signs all over the country and helps in improving intercommunication across the country.

Learning to sign

If possible, contact the regional office of the Ali Yavar Jung Institute for Hearing Handicapped and get a handbook of sign language adapted to your language. Or if it is difficult to reach them you can also use the local signs and gestures, and invent more signs of your own.

The All India Federation for the Deaf has developed '**work survival signs**' which are specific for certain words and can also be joined to form sentences.



Phone



Room



Think



Know

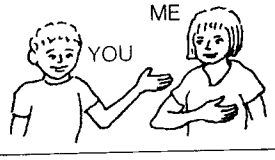
On the next few pages we give ideas for making up signs, and examples for common words. Most are signs used in American Sign Language. You will want to **change them to fit the gestures, customs and language of your area**. Here are some ideas:

- **Choose signs that will not offend the local people** (Deaf people already have a difficult time being accepted).
- **Use local signs.** If the people in your area already have a gesture or sign for something, use that instead of a new or a foreign one. (India and Nepal)

In the USA a pointing finger is used to indicate different persons (me, you, her, them).



In India as in some countries it is not polite to point a finger, so an open hand is used.



The American sign for NO is this:



Some countries use this sign for NO:



In Jamaica NO and NOT are often said by a negative look and shake or tilt of the head.

NO
NOT ME



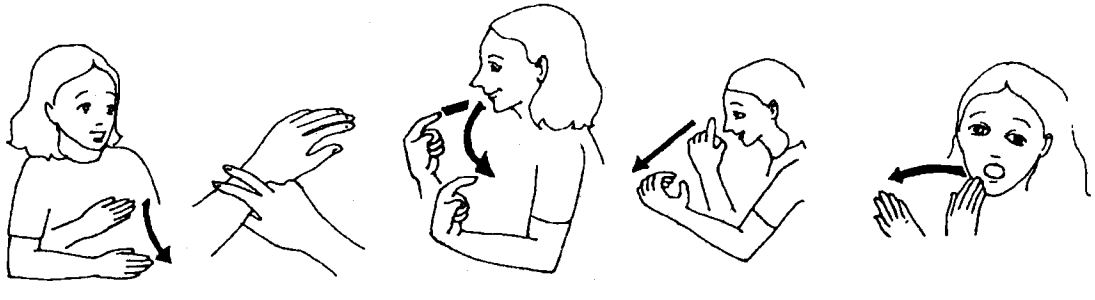
The American sign for SLEEP is this:



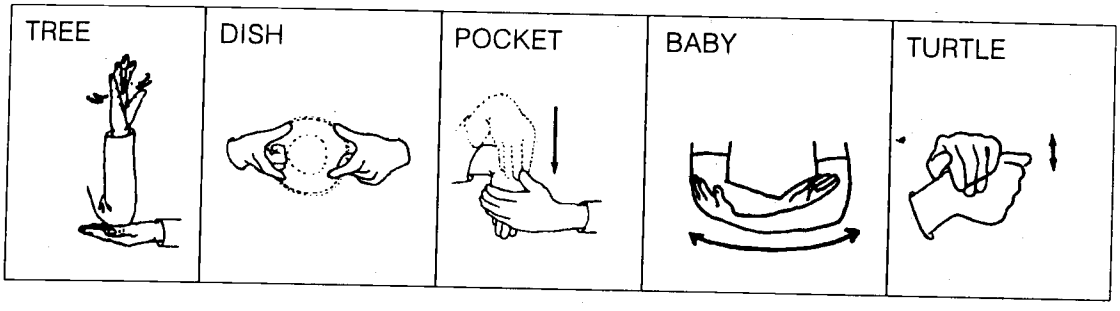
In Nepal this sign is used for SLEEP. It is understood almost everywhere.



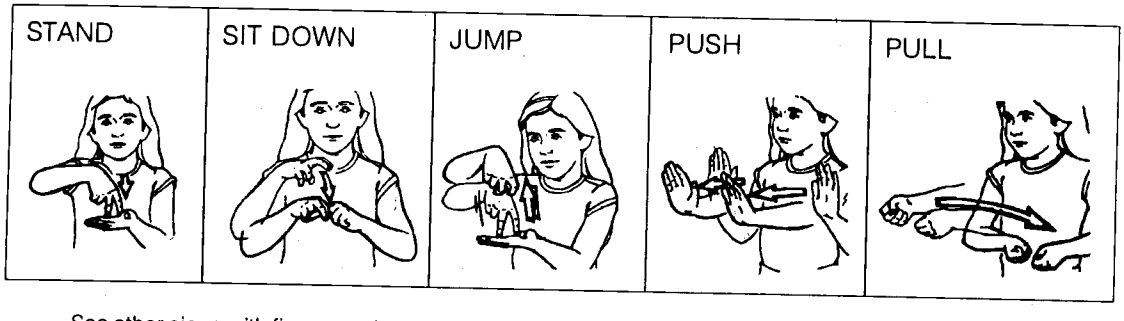
- **Use hand shape, position, movement, and direction to make different signs.** The expression on the face also adds to meaning.



- Try to **make signs look like the things or actions they represent.** To do this you can use a combination of **hand shapes** and **movements.**

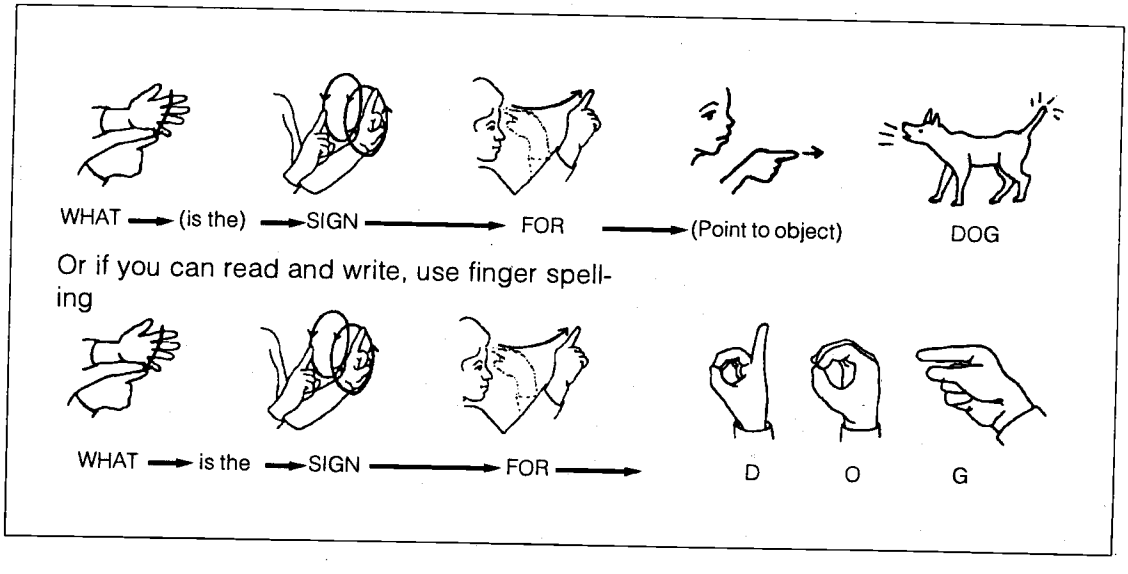


- Figure out patterns and series of similar signs for related things and actions, and for opposites, For example



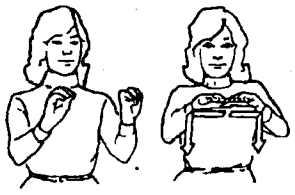
See other signs with fingers as legs on p.272.

- Learn new signs by pointing to things



- **Combine signs for things and actions to communicate ideas or sentences.** The arrangement of words does not need to be the same as in the spoken language- and you can leave out 'extra' words like "the" and "a". Also, words like "to" or "from" can often be left out or can be indicated by the direction of a motion.

Set the table



PUT or SET → TABLE

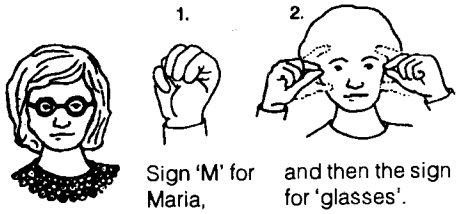
Will you give me a banana, please?



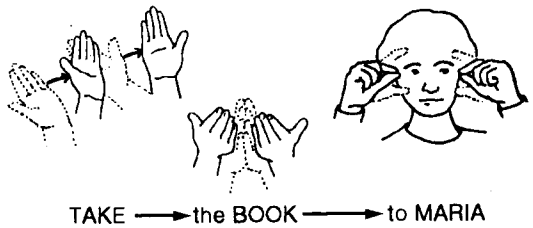
BANANA → GIVE → YOU to ME → PLEASE
(peeling motion)

- You can make up signs for people's names by **using the first letter of their name,** by showing something that stands for that person, or both.

If Maria looks like this, you might sign her name like this:



Sign 'M' for Maria, and then the sign for 'glasses'.



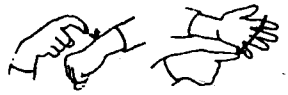
TAKE → the BOOK → to MARIA
(Move hands in direction it should be taken.)

HOW TO ASK QUESTIONS

WHAT

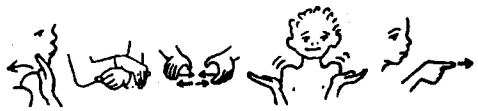


What time is it ?



TIME ? → WHAT

What did you do last night ?



PAST → NIGHT → DO → WHAT shrug → YOU

WHERE ?



OR

WHEN ?



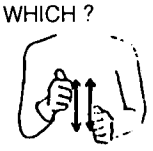
WHY ?



WHO ?



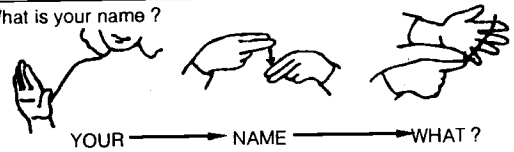
WHICH ?



HOW MANY, HOW MUCH ?

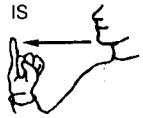


What is your name ?



YOUR → NAME → WHAT ?

IS



NOTE: 'Is', 'are', 'am', 'was', and 'were' are often not used, as in "What is your name ?"



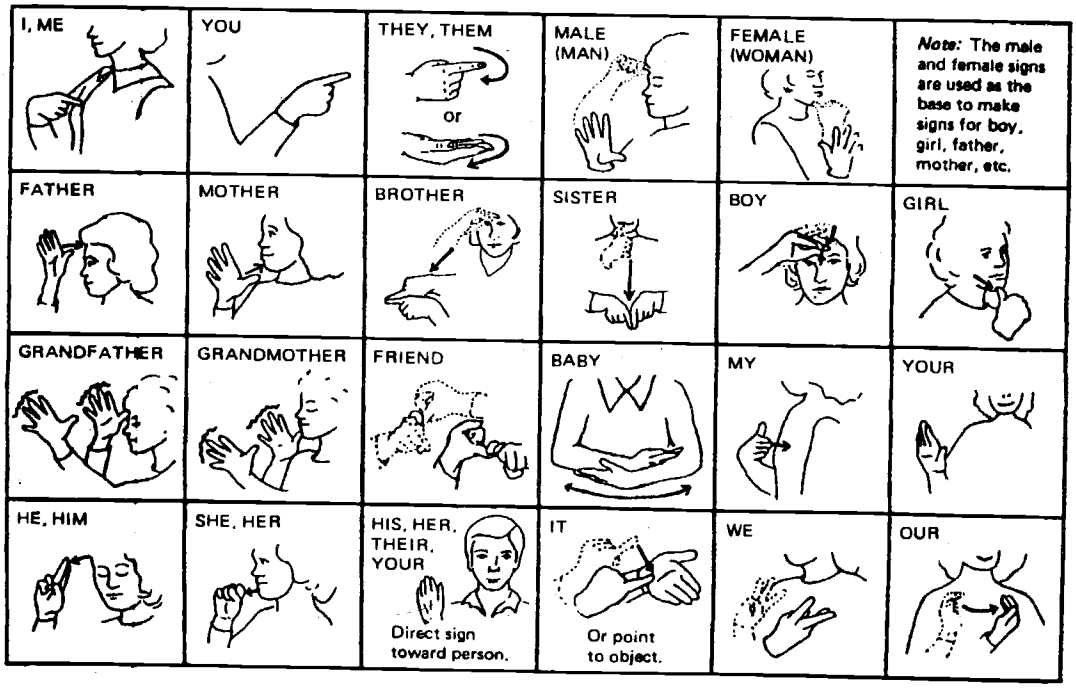
QUESTION MARK
Use before or after a statement to turn it into a question. (motion of milking cow)

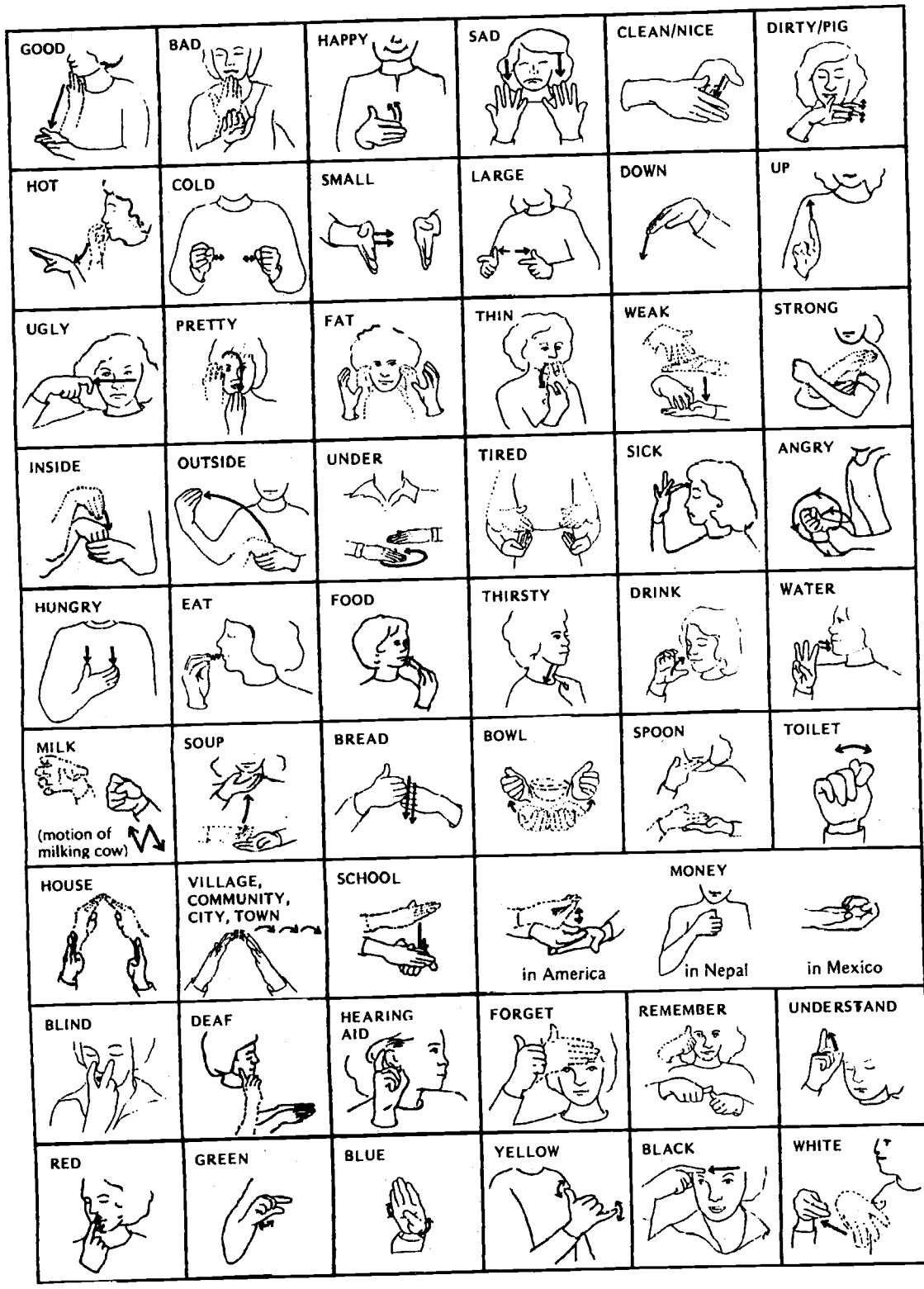
EXAMPLES OF SIGNS

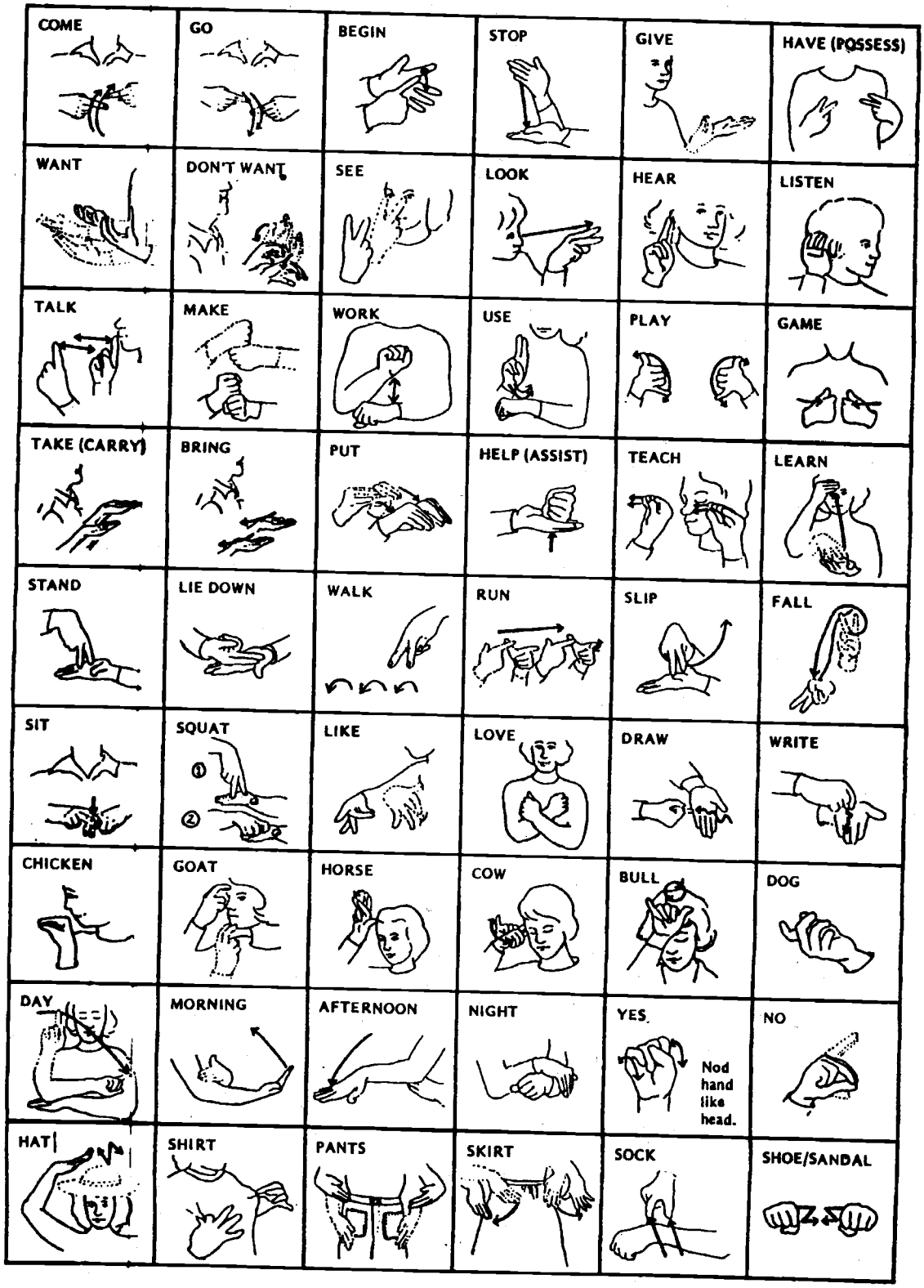
The signs shown here are mostly used in the United States (American Sign Language). A few are from Nepal, Jamaica, and Mexico, because these seem easier to understand. They are also used in India. We have chosen signs for things and actions that should be useful for early learning and group games with children. We include them mainly to give you ideas. Change and adapt them to better fit your area.

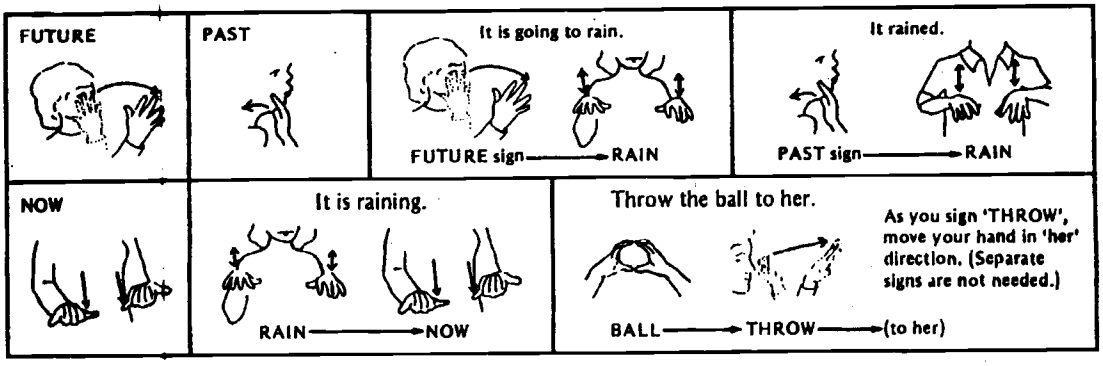
- **Arrows (———>)** in the drawings show the direction of hand movement to make the sign.
- **Wavy lines (^^^^^)** used with a sign mean a shake of the hand or fingers.
- **Dotted lines (.....)** show how the sign looks when it begins.
- The **darker sign** is how it looks when it ends.

Note: A few signs shown here are based on letters of the alphabet (for example, 'it' uses the letter 'i', and 'we' the letter 'W'). Change these signs if you speak a different language, or if you want to avoid signs based on letters.

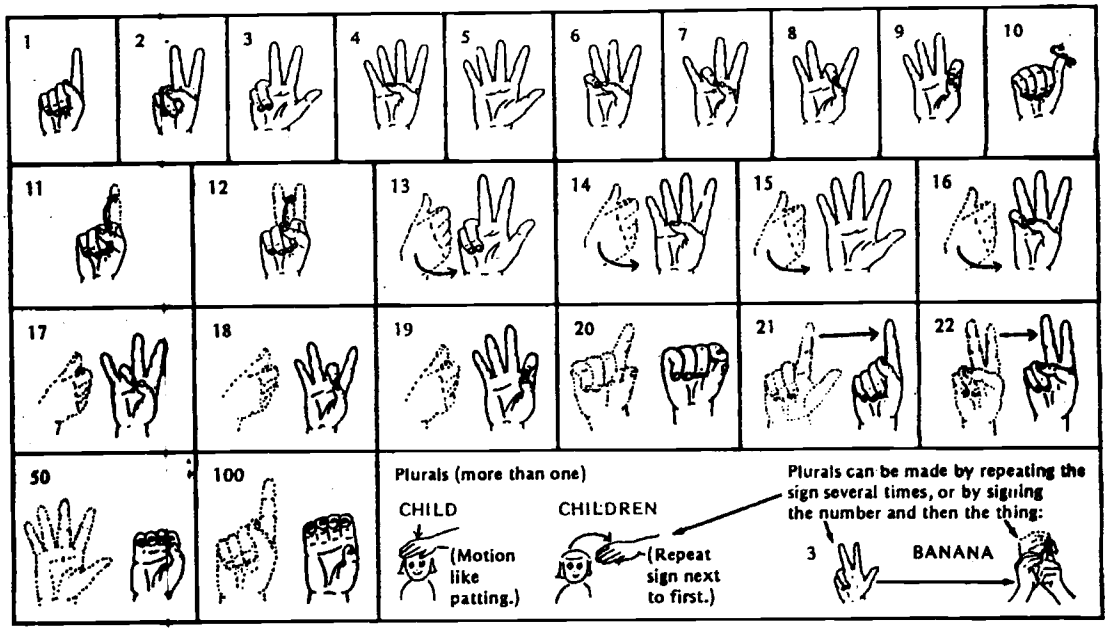



GOOD
BAD
HAPPY
SAD
CLEAN/NICE
DIRTY/PIG
HOT
COLD
SMALL
LARGE
DOWN
UP
UGLY
PRETTY
FAT
THIN
WEAK
STRONG
INSIDE
OUTSIDE
UNDER
TIRED
SICK
ANGRY
HUNGRY
EAT
FOOD
THIRSTY
DRINK
WATER
MILK
(motion of milking cow)
SOUP
BREAD
BOWL
SPOON
TOILET
HOUSE
VILLAGE, COMMUNITY, CITY, TOWN
SCHOOL
MONEY
in America
in Nepal
in Mexico
BLIND
DEAF
HEARING AID
FORGET
REMEMBER
UNDERSTAND
RED
GREEN
BLUE
YELLOW
BLACK
WHITE

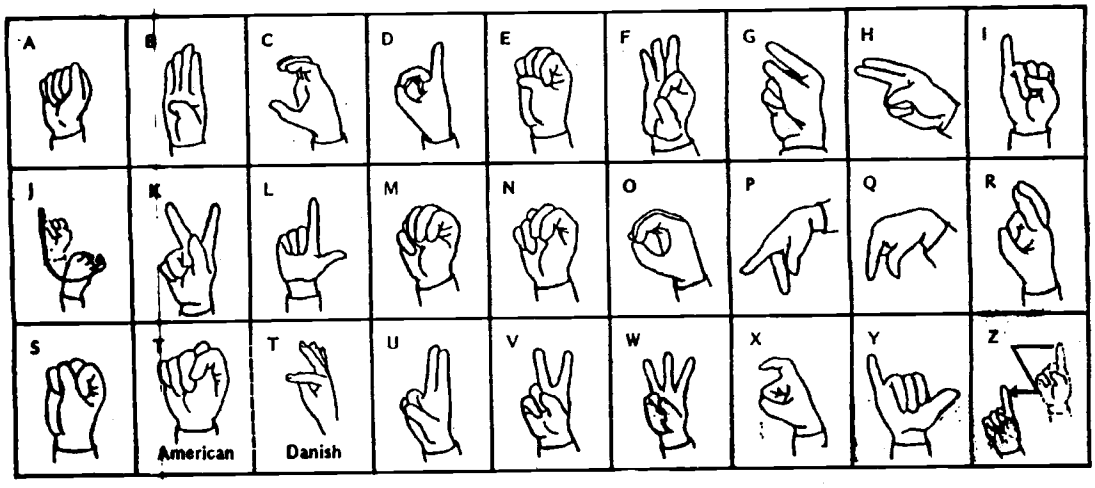

COME
GO
BEGIN
STOP
GIVE
HAVE (POSSESS)
WANT
DON'T WANT
SEE
LOOK
HEAR
LISTEN
TALK
MAKE
WORK
USE
PLAY
GAME
TAKE (CARRY)
BRING
PUT
HELP (ASSIST)
TEACH
LEARN
STAND
LIE DOWN
WALK
RUN
SLIP
FALL
SIT
SQUAT
① ②
LIKE
LOVE
DRAW
WRITE
CHICKEN
GOAT
HORSE
COW
BULL
DOG
DAY
MORNING
AFTERNOON
NIGHT
YES
Nod hand like head.
NO
HAT
SHIRT
PANTS
SKIRT
SOCK
SHOE/SANDAL



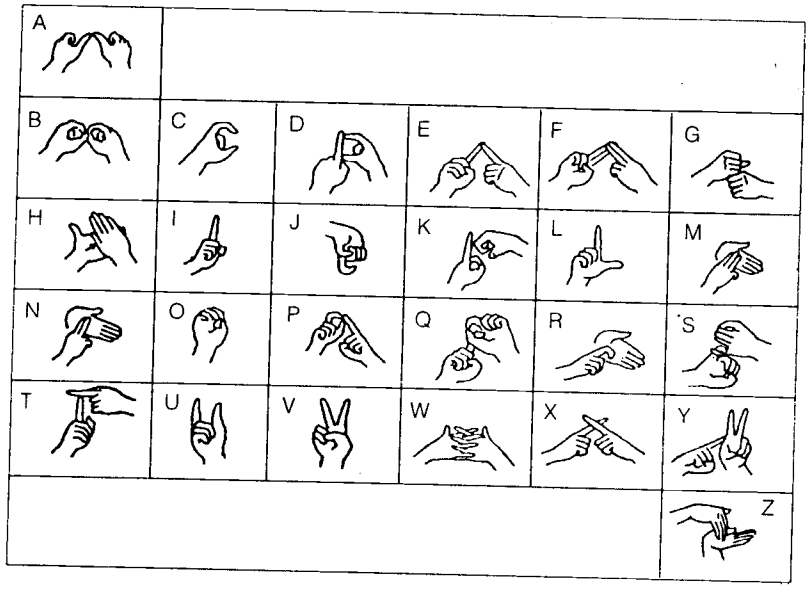
NUMBERS (one of many systems)



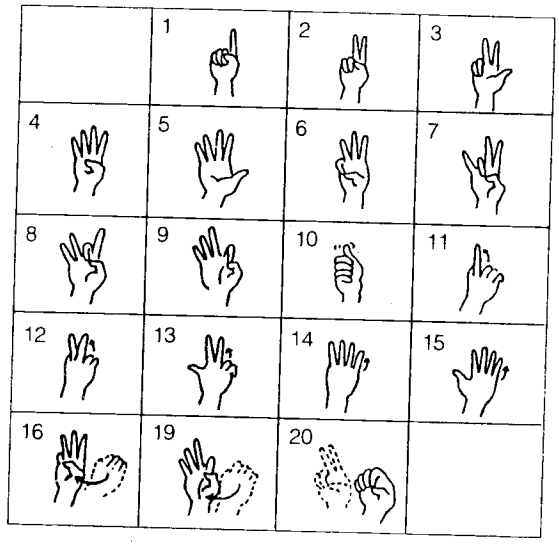
ONE-HANDED SIGN ALPHABET (American)



ENGLISH TWO HAND FINGER SPELLING



NUMBERS



NOTE: Write to Ali Yavar Jung National Institute for Hearing Handicapped, K.C. Marg, Bandra Reclamation, Bandra, Bombay 400 050. for INDIA MANUAL ALPHABET for your language and other publications on Deafness.

Total communication

Total communication is an approach that encourages a child to learn and use **all the different methods that work well for that child in her particular community.** This might include any or all of these:

- the child's own gestures
- sign language
- Drawing, reading and writing
- finger spelling
- whatever hearing the child has, to develop lipreading and speech.

Important: 'Total Communication' as we use the term, does not mean that all the above methods are used for every child. It means that we **try all the methods** that might work for a child. Then we **work with whatever methods will help the child communicate as easily, quickly and as fully** as possible with her family and the community. It is an approach that is friendly flexible and adaptable to individual local needs.

Helping a child learn 'total communication'

- The learning place should be well lighted, so that the child can see your hands, face and lips.
- Face the child when you speak to her, and be sure she is watching you.
- Talk to her a lot, even if she does not understand. Talk with your hands, face and lips and encourage her to watch them all.
- Speak clear and loud, but **do not shout** and **do not exaggerate the movement of your mouth and lips**. This will help her learn to recognize normal speech.
- Be patient and repeat things often.
- Be sure to let her know that you are pleased when she says something or does something well.
- Encourage her to make whatever sounds she can. This will help her to strengthen her voice for possible speech.
- Have a lot of toys, pictures and other things ready to use in helping her learn the signs and words for them.
- Make learning to communicate fun, include other children in games 'Simon says' that help children use their eyes, ears and bodies and copy each other (see p. 384.)
- Play games that exercise the child's lips, tongue, and mouth ***muscles***. In a deaf child, these muscles can get weak. This not only makes speech more difficult but can make the child's face look dull., or without expression. For activities to strengthen and control the mouth and lips, see p. 384 and 385.

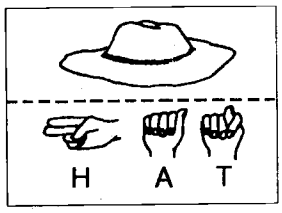


- Make a list of the words that other children her age use, and that you most want the child to learn. Include:

- **useful words for learning and games:** yes, no,thank you, please, what, do,don't, like,want
- **common and interesting things:** body parts, animals, clothing, foods
- **action words:** come, go, eat, drink, sleep, give, put, see, hear, wash, walk, run, play, pee
- **description words:** small, big, up, down, fat, thin, good, bad, hot, cold, day, night
- **people:** you, I, he, she, it, we, they, Mama, Papa, Juan, Maria and other family members

Start with a short list and gradually make it longer. Use the words often, in daily activities (feeding,bathing,dressing) and in play. Have the whole family learn the words on the list and how to make the signs for them. Encourage everyone to use the words and signs together, not only when they talk with the child, but when they talk with each other, and for all the things they do in the home. This way the child will learn about language by playing, watching,listening (as much as he can) and finally by copying – the way most children learn language.

- As the child gets a little older help her become familiar with letters and written words. You can write the first letters or name the things on different objects around the home. Or make pictures of things with their names in big clear letters. Or make pairs of 'flash cards' so the child can match pictures with words. This will help the child understand hand signs that are based on letters. It will prepare him for learning the alphabet in writing and signs, and for learning to read and write.



WARNING; Beware of programs that teach only oral communication

In many countries, schools for the deaf still try to make all children learn only 'oral communication' (lip reading and spoken words). The results are often disappointing, or even harmful, especially for the child who was born deaf. Lip reading at best gives a lot of problems.'A skilled lip reader can only understand about 40 to 50 percent of English words, and has to guess at the rest.(For example, "Mama" and 'Papa' look exactly the same on the lips). Even if the child does learn to lip read and speak some often his words are unclear or sound strange. As a result, when he grows older, often he prefers not to speak.

The biggest problem with teaching only oral communication is that it slows down a child's language development at the age when children learn language fastest (age 1 to 7 years). A deaf child usually learns to lip read and speak only 5 or 10 words by age 5 or 6. By that age, the same child can easily learn over 2,000 signs – as many words as a hearing child speaks.

Studies have shown that deaf **children who learn to use gestures and signs can communicate easier, earlier, and more fully than those who are taught only oral communication. Learning sign language and other forms of communication first actually makes it easier for a child to learn to speak and read lips.**

For all these reasons, **more and more experts and organizations of deaf people recommend teaching most deaf children a combination of communication methods, including some form of sign language.**

- 'Total communication' is not new. In villages in many parts of the world, deaf and hearing persons find imaginative and effective ways to talk with each other. They figure out a system of hand signs, objects, face movements, pictures and certain sounds of words. As a result, deaf persons often manage fairly well in the community. They can 'say' and understand a lot.

PREVENTION of deafness

- Take steps to **prevent ear infection** (teach the child not to blow her nose hard when she has a cold). **Treat ear infections at once** when a child gets them. If the child has frequent ear infections, see a health worker or 'ear doctor'. Do not put leaves or plugs of cotton in an infected ear. Let the pus run out. See p. 439 in *Where There Is No Doctor*.

- **During pregnancy, do not take medicines that might harm the baby.** Tell the health worker or doctor you are pregnant, and ask him to check if the medicine he prescribes is recommended during pregnancy.

- **Vaccinate** girls and women against **German measles** (rubella) before they get pregnant(but never when pregnant). Or let young girls catch German measles by letting them play or sleep with a child who has them. This will give them a 'natural' vaccination. Pregnant women should avoid getting near anyone with German measles.

- Have regular medical **check-ups during pregnancy**

- **Eat as well as possible before and during pregnancy,** use **iodized salt** and include: **foods rich in iron** and other **vitamins** and **minerals.**

- Look for signs of **cretinism** in the baby, and **treat it early** (see p. 342)
- **Vaccinate** the baby against **measles** (and, if possible, **mumps)**
- Take precautions to prevent brain damage and cerebral palsy **(see p. 121 and 122)**
- Never put, or let the child put, **pointed objects in the ears.**
- **Avoid** being near very **loud noises**. When a child cannot avoid them, teach him to cover his ears, or use ear plugs.

Words to the family of a deaf child

Deaf children can grow up to be loving and helpful sons and daughters, like other children. Try to let your child grow up. Give him the same rights and responsibilities as other children his age.

If there is a chance for your child to go away to a school for the deaf, if it seems right, try to let him go. Deaf children learn in different ways than other children. The special school may provide more opportunities. However, if your child is doing well at the village school, has a teacher who understands and helps him, and has many friends, he might do better there. Help him understand the choices and see what he thinks would be best. Be sure he knows he has a loving family to come home to.

After they finish school, deaf children can do many different kinds of work. Deaf people have become accountants, teachers, lawyers,farmers, health workers , clerks, skilled crafts workers and doctors. It is worth the effort to see that deaf children and adults get training and find work.

Be careful that after he has grown up, you do not treat him as a child. He might seem younger than his age. But the best way to help him grow up is to expect him to grow up.

When deaf children grow old enough to marry, they often choose to marry someone else who is deaf, for they can understand each other better. They can have children and raise them well.**Usually a deaf mother and father have children with good hearing.**

It is difficult to be deaf. You can help persons who are deaf by letting them communicate in ways they find easy, and by trying to learn to communicate with them yourself.

CHAPTER 32

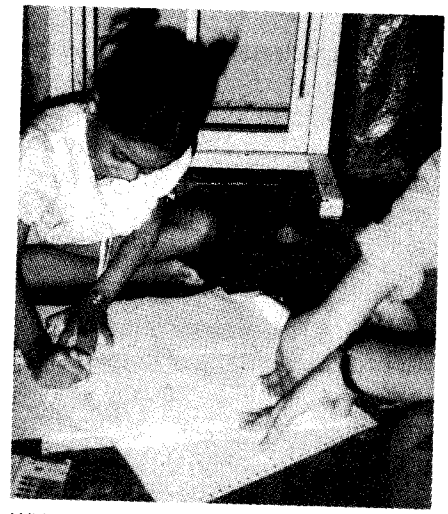
Mental Retardation

Down Syndrome, Iodine Deficiency Disorders and Other Causes

What is mental retardation ? Look at your hands. All fingers are not the same length or the same shape. Some are long while others are short. Similarly people differ in their capacity to carry out different functions. Some people are cleverer than others. Some people can write great novels or win prizes for science but most of us cannot do so. Some of us are better at mechanical work and others at book keeping. Mentally handicapped people are less clever than the rest of us.

Mental retardation, is a delay, or slowness, in a child's mental development. The child who is mentally handicapped learns things more slowly than other children of the same age. He may be late at beginning to move, smile, show interest in things, use his hands, sit, walk, speak, and understand. Or he may develop some of these skills more quickly, but be slower in others.

The movements of the different parts of the body are controlled by the brain. In a mentally handicapped child the brain develops very slowly because it has been damaged, due to various reasons. This can happen before, during or after birth. Because of this damage the child's development is slow.



With help, some retarded children can learn to read and write and do many of the things that normal children do. (Photo of a child with Down Syndrome. JAN MADHYAM, New Delhi, India.)



Vidya is 10 years old. She is short for her age. She cannot speak clearly. She cannot put on her clothes or bathe by herself. She does not fully understand when others talk to her. Other children think that Vidya is 'dull' so they do not want to play with her. At times they also make fun of her. Her mother says that Vidya is very different from other children. Her development, specially mental development has been slow. She behaves like a 4 year old child. Vidya's brothers and sisters help her with her daily needs. Her family is worried because she is unable to learn or remember simple things. They have taken her to temples and traditional healers. She has also been given many medicines by different doctors. But nothing has been been able to make her a normal girl of 10 years.

It is clear that Vidya is not like her sisters, brothers, or other children her age. She has low intelligence. Such children are called mentally retarded or mentally handicapped.

People in our country have many beliefs about what causes mental retardation. Some of these beliefs listed below also apply to other disabilities.

- Mental retardation is due to KARMA or fate. (a disabled child is born as punishment to the parents for the sins they have committed in their last birth).
- It is a result of Black Magic, spells, evil eye etc.
- These children are born as a result of weakened semen.
- The effects of the solar eclipse during pregnancy or at the time of birth results in the child being born mentally retarded.
- Some communities even consider a mentally retarded child as an AVATAR or reincarnation of GANESH.

A child who is mentally handicapped faces difficulties in learning, in using past experiences for the solution of present problems. He finds it difficult to remember, to understand and adjust to different situations. He does not develop mentally or even physically at the same rate as other children of the same age. For example: a child may be 8 years old but may only have the abilities of a 4 or 5 year old child, or a 12 year old child may behave like a 4-5 year old or even less.

Mental retardation is only one of the reasons for slow development in children. A child who is blind will be slow in learning to reach and move about unless he has extra help and encouragement. A child who is deaf will be delayed in learning to communicate unless he is helped to learn to 'talk' in other ways than speech. A child who has a severe physical disability is often slow in developing use of both his body and mind. Because developmental delay is common with so many disabilities, we include discussion of it in several separate chapters.



Mental retardation cannot be cured. However, all mentally retarded children can be helped to learn skills and progress in many ways depending on the severity of retardation. The earlier special help or 'stimulation' begins, the more ability the child is likely to gain.

Mental retardation ranges from **mild to profound.** Many of these children, if given suitable and timely training may learn to take care of their basic needs like drinking, eating, bathing, dressing etc. There will however be some children who will always need to be cared for in some ways. Depending on the degree of mental retardation, early identification, timely intervention and adequate opportunities for training and developing their skills, many of these children can grow up to care for themselves in most ways and learn to live as independent, responsible and active members of the community. The child who is moderately, severely or profoundly retarded, as he grows older, may be able to learn only a few skills, as compared to a child who has mild mental retardation. **A vast majority of people who are mentally handicapped fall in the catagory of mild mental retardation.**

Information on helping a child who is mentally retarded or developmentally delayed is in Chapters 35 to 41. Chapters 35 and 36 discuss **early child development** and ways to help or 'stimulate' a child to learn early skills (use of the senses, movement, and communication). Chapters 37 to 40 discuss **learning for self-care** (feeding, dressing, toileting, and bathing). Chapter 41 discusses **child behavior,** and ways to encourage *behavior* that helps learning.

Other ideas for helping retarded children are in the CHILD-to-CHILD activity on pages 536 to 539. The needs and problems of mentally retarded children as they become sexually grown up are discussed in Chapter 53, p. 599.

One important need that we do not include in detail in this book is **education for retarded children.**. Some possibilities are discussed in Chapter 54, on education. But often special teaching methods and materials are needed. An excellent book is Special Education for Mentally Handicapped Pupils. (See p. 772) For toys that help a child learn, see Chapter 50. **The Portage Guide to Early Education,** (Jamaican adaptation; Hindi

translation by Dr. Tehl Kohli, PGI, Chandigarh) is used by several organisations in the country). Other useful books are **Towards Independence Series** – a series of 9 booklets on skill training for the mentally handicapped by the National Institute for the Mentally Handicapped, **Home Training for Children with Mental Handicap** in Hindi and English, Genetics Department, All India Institute of Medical Sciences. New Delhi.

A child is expected to perform certain functions at a certain age. If he is unable to do so it may be because his brain has not developed as it should have. Every child goes through certain stages of development. The chart in chapter 35 on the normal development of a child can be used as a guide to identify if a child has learnt a particular skill at the appropriate age. If he has not, then there is a delay or slowness in his development.

A child is generally able to learn the following functions by a certain age.

INDEPENDENT FUNCTIONING : A child can feed himself with soft foods with a lot of spilling, can pull off clothing and put some on, tries to help with bathing or hand washing but still needs a lot of help, indicates toilet accidents and may also indicate toilet need.

PHYSICAL FUNCTIONING: May climb up and down stairs but not alternating feet, may jump, balance briefly on one foot, can pass objects to others or put them elsewhere when told, may do and solve simple puzzles (form- board) without help.

COMMUNICATION: May speak two or three word sentences, name simple common objects like ball, car etc, can understand simple directions like 'sit here' 'put on your chappals'etc. knows people by name. If the child cannot speak he may use many gestures to communicate his needs or other information.

SOCIAL FUNCTIONING: May interact with others in simple play activities, usually with one or two others, unless guided into group activity, likes some people more than others and shows it.

Individuals with an IQ **(intelligence quotient)** of 70 or less are generally considered to be mentally handicapped. If a child is unable to perform the functions mentioned above by the the following ages, he is generally considered to be mentally retarded:

3 years:	the level of retardation is	*"MILD"*	IQ- 50 to 70
6 years:	the level of retardation is	*"MODERATE"*	IQ- 35 to 50
9 years:	the level of retardation is	*"SEVERE"*	IQ- 20 to 30
12 years:	the level of retardation is	*"PROFOUND"*	IQ- 20 and below.

So make sure that you consult your local rehabilitation worker or a doctor before concluding that the child is mentally handicapped. This generally happens in the case of slow learners who fall into the **borderline** catagory.

A child who is considered to have **borderline intelligence** has the ability to study upto at least the 8th standard with proper care and training. Such children (IQ between 70 - 90) are generally identified at the school going age.

It is important to remember that with early detection and proper training mentally handicapped people can learn many skills.

CAUTION : However it must be remembered that a child may do some of these things a little later than he should. There may be minor deviations in the child's developmental level, because every child grows and develops at his own pace. It may also be because the child has some other disability.

As an adult, the **'mildly'** handicapped person's level of intelligence is that of an average 8 to 11 year old child. His social adjustment is very much like that of an adolescent, though he tends to not have the imagination, inventiveness and judgement of the adolescent. With early diagnosis, parental assistance and special educational programmes, majority of them can adjust socially, master simple academic and occupational skills and become self supporting citizens. In the rural areas where no special education facilities are available these children may be taught to learn skills like tending to the cattle, milking, farm work and other local trades.

The maximum number of mentally handicapped people fall in this category.

An adult **moderately** handicapped person has the intelligence of a 4 to 7 year old child. Some of them may be taught to read, write or even speak fairly well. Physically they seem clumsy and ungainly, they also suffer from bodily deformities and poor coordination of the legs, arms, hands and fingers. Some of them may be hostile or aggressive. With timely intervention they can be trained to achieve some amount of independence in self care, acceptable behavior and economic usefulness in the family work or in a sheltered environment. (see chapter on WORK).



Solving a jigsaw puzzle. (Photo: A mentally retarded adolescent at SAMADHAN, NEW DELHI.)

In a person with **severe** mental handicap, speech and movements of the arms and legs are severely affected and sensory defects are common. They can develop limited levels of personal hygiene and self help skills. But they require supervision through their lives in managing simple skills. Many of them can be trained and gainfully occupied in simple repetitive tasks.

The **profoundly** mentally handicapped person can learn only the simplest of tasks with great difficulty. Speech is at the rudimentary level. They also have severe physical deformities, problems of the central nervous system and retarded growth, no speech, deafness; fits and other physical problems are quite common. Their resistance to disease is very low and their life expectancy is short. People with profound mental handicap need to be cared for as long as they live.

MENTAL RETARDATION IS A CONDITION, NOT A DISEASE

IT CANNOT BE CURED BY: Medicines, injections or surgery, Brain Tonics (for example: Encephabol. It is often used for reducing hyperactivity in children), Marriage, Traditional healers, pundits or priests, or Black Magic.

MENTAL ILLNESS is different

Some people confuse 'mental retardation' with 'mental illness'. But they are very different. A person who is mentally ill may have normal or high intelligence, and may be highly educated. But because of stressful experiences, or some illness affecting the brain, his behavior becomes strange even though he knows how to behave normally. But when a person who is mentally retarded behaves in an abnormal way, it is usually because he has not learned the correct way. He needs to be taught. The mentally ill person needs special help from a qualified doctor – a Psychiatrist to overcome his illness and return to normal everyday life and behavior. **Persons with mental illness are like persons with any other illness. Often they cannot control their strange behavior. We should not blame or punish them, but give them love, protection, and understanding.**

CAUSES OF MENTAL RETARDATION

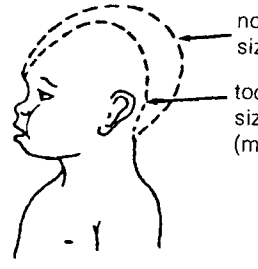
In this chapter we look at some of the causes of mental retardation.

In most cases it is not known what causes mental retardation. However, there are many known causes, and many types of mental retardation can be prevented.

Brain damage can happen either before, during, or after birth. In addition to being retarded, these children may also have cerebral palsy, blindness, deafness, or fits. Common causes of retardation from brain damage are discussed in Chapter 9,

There are many factors that lead to mental retardation. They can be **GENETIC (hereditary) or ENVIRONMENTAL**

- Often the cause is not known.
- Sometimes there is a **' mistake' in the ' chromosome'** or the tiny chemical messages from the father and the mother that determine what a child will be like (inheritance). This is what happens in Down Syndrome.
- Some children are born with a very small brain, or the brain does not grow or work normally as in **microcephalus**
- In **hydrocephalus** the child has a large head. Often it is in combination with Spina Bifida (see page 195).



A child with microcephaly (small brain) is mentally slow and often also develops certain physical problems. For measurements of head size, see p. 43.

- Sometimes the mother did not **get enough of a certain food or mineral during pregnancy**. (see Cretinism ,page 342)
- Rare conditions like **Phenylketonuria**, where the child's body cannot use food properly and the brain may be damaged by the poisons produced in the body.
- **German Measles** during early pregnancy, exposure to X Ray, Syphilis, urogenital and other maternal infections.
- **Alcohol and drugs; medicines taken without doctor's prescription (even aspirin).**
- **Meningitis** (brain infection) from bacteria; tuberculosis, or malaria, encephalitis most often during early childhood.
- **Head injuries** caused, for example, by car accidents, being kicked, fall from a high-wall or slap on the head etc.
- **Brain tumor, poisoning from lead, mercury, pesticides** (see p. 15), certain medicines and food and some forms of **muscular dystrophy** or atrophy (see p. 124)
- **Severe Jaundice**
- **Epileptic fits**
- **Lack of stimulation or emotional deprivation, environmental deprivation.**

In India as in many other parts of the world, the most common cause of mental retardation are brain damage and Down Syndrome. But in some mountainous areas, it is very often caused by lack of iodine in food and water (see p. 342).

There is no treatment for mental retardation. We often do not know the exact cause. But we need to know the cause if possible so that it can be prevented from happening again. There is need for genetic counselling if there is already a disabled child in the family. (see p. 503) We need to help the child develop the best he can. However, in some cases, changes in diet or prevention of further poisoning can make a big difference. If a child has any signs of cretinism or seems to be gradually losing mental ability, try to get expert medical advice. A child with **microcephaly** (small brain) is mentally slow and often also develops certain physical problems. For measurements of head size, see p.43.

Some RISK FACTORS which may increase the likelihood of a child born with a mental handicap.

- Maternal age – the risk of giving birth to a child with DOWN SYNDROME increases when the mother is above 35 years of age.
- Poor or inadequate maternal nutrition.
- Pregnant women working with toxic substances
- Consanguinity (marriage between close relatives)
- Premature or prolonged and difficult labour and brain damage due to instrumental delivery.
- Shortage of oxygen to the brain during birth.
- Use of drugs like Oxytocin which hasten childbirth (increase uterine contractions) does not allow the uterus to relax so that the baby can have oxygen.
- Low birth weight
- Illness immediately after birth, eg: fits, jaundice.

Prevention of mental retardation is discussed with its different causes. See especially cerebral palsy (p. 121), Down syndrome (given below), and cretinism (p. 342).

Many mentally retarded children may look like normal children. It is only from their behavior that they can be identified as being mentally retarded. Because of this they are often called **MAD** and ridiculed. It is only in specific types of mental retardation like Down Syndrome, Cretinism, Hydrocephaly or Microcephaly that the children look different.

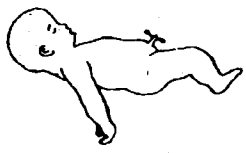
Here we briefly discuss two types of mental retardation.

DOWN SYNDROME

In many areas, Down syndrome – or 'mongolism' – is the most common form of mental slowness, or retardation. Their intellectual functioning is generally **moderatly to severely retarded**. These children are slower than others in learning to use their bodies and their minds. There are also certain physical signs or problems. (This combination of various signs is called a 'syndrome'.) The baby does not develop normally in the womb because of an error in the 'chromosomes' (material in each cell of the body that determines what a baby will be and look like).

These are the typical signs of Down Syndrome (but **not all** the children have **all** these signs):

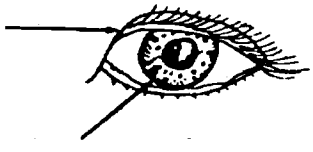
- At birth, baby seems floppy and weak.
- Baby does not cry much.
- The baby is slower than other babies her age to turn over, grasp things, sit up, talk, walk.
- When suddenly lowered, the baby does not react by spreading her arms, as a normal baby does.

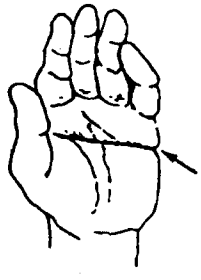




- eyes slant upward; sometimes cross-eyed or poor sight.
- ears low
- small mouth, hangs open; roof of mouth is high and narrow; tongue hangs out.

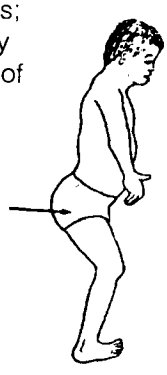
- A fold of skin covers the inner corner of the eyelid.
- The child is prone to frequent eye infections. Eyelids may be swollen and red.
- The iris of the eye has many little white specks; like sand. These usually go away by 12 months of age.



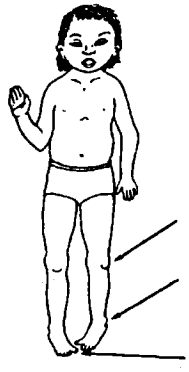


- short wide hands with short fingers. The little finger may be curved, or have only one fold.
- one deep crease across the palm (This is also seen in 5% of normal children).

- short or small head, wide and flat in the back
- sometimes dislocated hips



- flat face
- small nose, flat between the eyes



- short neck
- rounded shoulders
- short arms and legs
- knee-cap slips to one side
- 'pigeon-toed'; flat feet
- big toe far apart from other toes

Other possible signs:

- Elbow, hip, and ankle joints may be very loose and flexible.
- One out of 3 has heart problems.
- May develop leukemia (blood cancer in rare cases).
- Check older children for hearing and seeing problems.
- One in 10 children have deformed neck bones which can slip and pinch the nerve cord in the spine. This may cause sudden or slow but increasing paralysis – or sudden death.

CAUTION: **Such children should generally avoid participating in strenuous games which might make them jerk their necks. Somersaulting is particularly dangerous.**

(Care of children with Down and other forms of mental retardation) Mental retardation in children with Down syndrome can be moderate, or severe. Some children never learn to speak. Others talk (and often love to talk). Many can learn to read and write. Most of these children are very friendly and affectionate, like other normal children and behave well with people who treat them well. Even those who are more severely retarded, with help and good teaching usually learn to take care of their basic needs, and to help out with simple work. They can live fairly normally with their families and communities.

In rural areas particularly, they can learn to do many jobs like working in the farms, tending to the cows and buffaloes, milking etc. Sometimes they do repetitive jobs as well or better than other people. In the urban areas they can be gainfully employed in any industry where there is need for simple repetitive jobs like sanding and polishing wood, packaging material etc.

But their physical and mental development is slower than normal. So parents and all those who take care of these children must be very patient with them and from a very early age do all they can to help them develop their mental and physical capabilities. To avoid or solve behavior problems, parents need to be very consistent in how they treat their children and in what they expect of them. The child needs a lot of praise and encouragement for things he does well (see Chapter 41).



In one village, a young man with Down Syndrome tending to the cows, a job he is happy to do. Other tasks he can do are fetch water from the river etc.

Some children with Down syndrome can go to school, but they will need extra help. It is important that teachers understand their problem and help other children to treat the child with mental handicap with respect. With understanding and extra help at school, the child will show considerable improvement. In rural areas where there may not be schools the child with Down syndrome may be educated at home through helping his family around the house and in the fields.

There are 3 main concerns in caring for a child with Down syndrome:

1. Help the child to develop her or his mental and physical abilities.
2. Protect the child from infectious diseases.
3. Prevent or correct deformities.

Here we will discuss the last 2 concerns. The first we will cover in other chapters.

IMPORTANT: For a child who has Down syndrome, or is mentally slow, be sure to **read all the chapters on early child development and learning basic skills, Chapters 33 to 42.**



A child with Down syndrome learns to match the rings according to their size and colour and place them correctly. Early Intervention Centre, SAMADHAN, New Delhi, India.

Protection from infections

Children with Down syndrome get sick more often than other children. They can easily catch colds, bronchitis, pneumonia, and other infections. So it is very important to protect their health. They are particularly prone to circulatory, gastrointestinal and respiratory disorders. If given timely medical care they have about the same life expectancy as normal people.



- **Breast feed** the child as long as possible. Breast milk has 'antibodies' that help the child to fight infections. (If he cannot nurse well, milk your breasts and feed him the milk, using a spoon or any way that works.)
- Like any baby, at 5 months start giving her other foods such as fruit, cooked mashed dal, eggs, and rice, but also continue to breast feed her. (Like any baby, weigh her each month at the health center to be sure she is growing well.)
- **Vaccinations** can protect her from many childhood diseases. A child with Down syndrome who catches measles or whooping cough can easily get pneumonia.
- **Early medical attention:** When she gets a sore throat, earache, or bad cough, take her to a health worker as soon as possible.

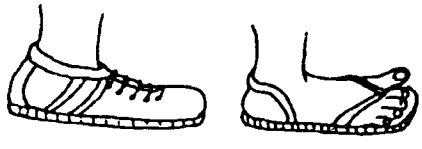
PREVENTION of foot deformities and other problems

- Check all newborns for possible *dislocated* hip, so that it can be corrected as soon as possible (see p.175).
- For the child whose big toe sticks out, do not use hard shoes that bend the big toe inward like this. It is better to wear soft shoes, or sandals, or chappals.





This can cause a painful dislocation here.



When the big toe sticks out a lot, its position can sometimes be corrected with surgery, so that shoes will fit without problems.

- If the child has **severe** flat feet, a special insole may help. (See p.132.)
- If any sign of paralysis or lack of feeling develops in the hands, feet, or body, get advice from an orthopedist or a neurosurgeon.

PREVENTION of Down Syndrome

One out of every 800 children is born with Down Syndrome and it occurs more commonly with mothers under 20 and over 35 years of age. Women who are 40 (or even over 35) should consider not having more children. A woman in her 20s has 1 chance in 2000 of having a baby with a Down Syndrome,whereas the risk for a woman in her 40s is 1 in 50. Also, if a couple already has one child with Down Syndrome they should seek **genetic counselling** before deciding to have another baby.

There are several tests that can be done during the early weeks of pregnancy to see if the baby will have Down syndrome, Microcephaly or any other physical deformity.

In such a case the parents can make a decision about having the child.

Tests recommended for high risk mothers – above the age of 35 years who already have one child with a disability.

Chorion Villous Sampling : this is done between 8 to 12 weeks of pregnancy, and the result is known within a week. This test is done at the All India Institute of Medical Sciences, New Delhi.

Amniocentesis: this test is done between 16 to 18 weeks of pregnancy. The result is known in about 2 to 3 weeks.

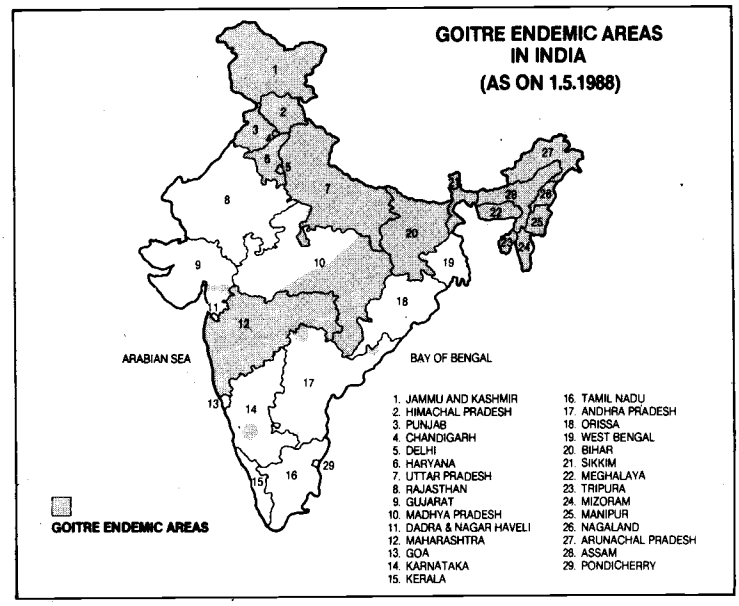
Ultrasonography: This test is usually done about the 16th week of pregnancy but can also be done at any time during the pregnancy. This test detects defects such as hydrochephaly, microcephaly and gross structural deformities.

CRETINISM (Hypo-Thyroidism) and other Iodine Deficiency Disorders:

Iodine Deficiency Disorders is one of the major problems in our country. Lack of iodine in a person can present itself in different ways. In areas where there is little iodine and a lot of people have Goitres, cretinism is common. In India about 150 million people are at risk from disorders caused by lack of iodine. Out of these 54 million have Goitre, 2.2 million are victims of **cretinism** and many more millions suffer from other disorders of the brain affecting speech and hearing, movement and gait etc.

There are areas in our country where more than 60% -80 % people have Iodine Deficiency Disorders. In these areas children are at most risk. Without iodine their physical growth is stunted. Often children have **difficulty hearing and talking**, squint in the eye or are **retarded mentally.** Although they do not show all the typical signs of cretinism, the cause is probably the same.

Cretinism is a delay in both mental and physical growth that comes when a child's body does not produce enough 'thyroxin'. Thyroxin is a substance, or 'hormone', that controls a child's growth and body functions. Without it, everything goes slower.



Ministry of Health & Family Welfare, Govt. Of India.

Thyroxin is produced by the Thyroid gland in the front of the neck. To produce thyroxin, the gland needs **IODINE.** Iodine is present in the soil and water. So our normal requirement comes from crops grown on iodine- rich soil. When the soil lacks iodine so do the crops grown and eaten by the people living in those areas. (Except for certain types of seaweeds there are no foods that are inherently rich in iodine). This is a problem particularly in the mountains and areas prone to floods, because iodine gets washed away from the soil due to floods, deforestation.



In an attempt to obtain more iodine, the thyroid gland sometimes grows very large, forming a swelling called a **GOITRE** which is the most visible sign of lack of iodine. (The Indian name which is used even today for Goitre is **GALGANDA**. Reference to Goitre is found in the ATHARVA VEDA dating back to 2000 B.C. This name was given by the early Hindu physicians and is described in the SUSRUTA SAMHITA.)

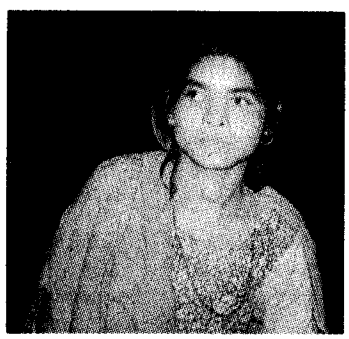
In areas where goitre is not common, cretinism also occurs. But it can occur for reasons other than lack of iodine. Cretinism can also be the result of birth injuries, or can occur in connection with other infectious diseases like measles, whooping cough and diptheria. But typical cases of cretinism are those where there has been severe lack of iodine in the mother before the birth of her child. Since the development of the unborn baby's brain takes place in the first 3 months of pregnancy, lack of iodine in the mother can lead to the baby being born :

- a deaf mute
- with psycho-motor retardation (lack of coordination of movements. example- walking etc.
- **with full blown cretinism.**Iodine deficiency in the pregnant woman can also be associated with increased incidence of abortion, still birth and infirtility.

If the mother's deficiency is minor, the child will still be affected, even though he may look normal. The damage to his brain usually shows up later in poor school performance and in his inability to perform normal every day tasks. Millions in our country suffer from this form of iodine deficiency and it affects the social and economic progress of the whole region.



Hypothyroid child: note the vacant look (Photo: UNICEF)



A deaf-mute child with squint and goitre (Photo: UNICEF)



A 12 year old child with cretinism (Photo: UNICEF)

SIGNS: Below we show some of the typical signs of cretinism and compare them with Down syndrome, which cretinism resembles in some ways. It is often difficult to tell if a new born baby has cretinism. She is often born large and then fails to grow normally. The baby may have feeding difficulties, or breathing difficulties or make noises because of the large tongue. She moves and cries little. By 3 to 6 months the mother often becomes worried because the baby looks dull, takes so little interest in things, sleeps so much, and is slow in all areas of development.

Signs of CRETINISM



- hair low on forehead
- puffy eyelids
- flat base of nose between eyes
- puffy face, hands, and feet
- fatty swelling here **(arrow showing exact place of swelling)**
- grows very slowly. Increasingly short for age.
- severe constipation (may go days without shitting)
- often deafness
- As the child grows the knees may get large and painful.

- temperature below normal
- thick, dry, cool skin

Signs seen in both CRETENISM and DOWN.

- slow mental and physical development
- widely seperate eyes
- round face with dull look
- tounge sticks out of open mouth
- short neck and limbs, wide short hands
- big belly and swayback
- often hernia of the navel



Signs of DOWN SYNDROME (most useful in differentiating it from CRETENISM.)

- hairline commences high on the forehead
- slant eyes with lid fold over inner corner

For other signs see page 339.



WHAT TO DO. Early and continued treatment with **thyroid medicine** helps improve growth, physical appearance and sometimes can reduce or prevent mental retardation. For best results, treatment should begin during the first month of life. For this reason, **as soon as you suspect that a baby might have cretenism, get skilled medical advice.**

To help the child develop mentally and physically, and learn basic skills, read chapters 31 to 42 and use the ideas that can help meet the child's needs. With early treatment and guided learning, many children with cretenism can learn to care for themselves and do simple but important work in the community. For ideas on managing constipation,see p.250.

PREVENTION. Iodine Deficiency Disorders is the single most important preventible cause of mental retardation. **Iodine as Iodized Salt and as Iodated Oil** can be taken orally by mothers in areas where goitre is common, to prevent and reduce the incidence of Cretenism (and deafness).

It is important to know and remember that though iodine is needed in tiny amounts, it is needed regularly. (About 1 teaspoonful of iodine is enough in a lifetime spanning about 70 years!). Iodised salt can be taken also by people who do not live in iodine deficient areas. The human body only takes the amount of iodine it requires and rejects the rest. Iodine in the salt can be destroyed by prolonged exposure to direct sunlight and moisture. Make sure you consume the salt within 6 months of buying it.

- For more details see **'20 Questions on Iodine Deficiency Disorders.'**

  Ministry of Health and Famiily Welfare, Government of India.) Simple kits for testing of iodized salt have been developed by – UNICEF and National Institute of Nutrition,Hyderabad.

- Control of Goitre is a National Programme of the Government of India.

Storing salt at home: The iodine content in the salt reduces only marginally with prolonged exposure.

CHAPTER 33

The Child with Several Severe Disabilities

Some children have a combination of ***severe disabilities***. We say they are 'multiply disabled'. For example, a child may be severely mentally **retarded**, and have little or no physical control of his body. He may also be blind or deaf, have fits, or have difficulty swallowing. Or he may have any combination of these disabilities – and perhaps develop severe ***behavior*** problems.



A child with severe disabilities.

Caring for multiply and severely disabled children is never easy; they need an enormous amount of time, patience, and love. In most communities, parents and close family members will be the main care providers. But **parents will need a lot of support from the community in order to care adequately for the child.** Unless parents have help, they are likely to find that the continual demands of caring for their child are too much. Even the most loving parents, after months and years of continuously caring for a severely disabled child, can easily become frustrated and angry. This is especially true when the child shows little progress or response, and grows up to be a physical adult with the needs of a young child.

It is not uncommon for a parent who for years has poured love and attention into a severely disabled, retarded child, to suddenly hit the child or in other ways begin to neglect or mistreat him.

Before we blame the parent for this, we should try to put ourselves in her position. She has given the child her total love and attention for years. She has waited for a change, for a smile, for some return of warmth and love. But the child remains like a newborn baby, becoming stiffer, more fussy, and more difficult to lift and care for as he grows. Any human being can only give so much without receiving something in return, some sign of recognition or appreciation. In time, the parent is overcome by the unfairness of the situation: the lack of appreciation, the constant demands, the lack of help, the hurt. She reaches her limit and hurts the child in return. Rather than blame her, we should try to understand her. Above all, **we should look for ways to help both the family and child – if possible, long before the mother or other family members reach their limit.**

COMMUNITY SUPPORT

There are several ways in which the community can give assistance to the family of a severely disabled child. In some countries (usually wealthier ones), the most severely retarded, multiply disabled children may be taken care in special care centers, or **'institutions'**. Although in may cases it is better for the disabled child to stay at home with own family, there are times when institutional care is needed. This may be because of difficulties in the home situation. Or it may be because the multiply disabled child requires more time and skill than the family can handle.

Institutional care, however, is very costly, and is usually possible only if government pays for it. Few governments of developing countries are willing or able to do that. This means that in poor countries – and especially in the rural areas – most support and assistance for these families must come from the communities themselves.

In areas where a **community rehabilitation program** exists, the program can play an important role. It will usually be neither desirable nor possible for the program to take complete or continual care of the severely disabled child. Yet, the program may be able to help in several ways:

- The community rehabilitation workers can regularly visit the home of the severely disabled child and give **suggestions, assistance,** and **friendship.**
- They can help make or provide **special seating** or **equipment** that can help the family to manage the child more easily.
- They can **teach the family** ways to stimulate the child's development and can plan with the family a step-by-step approach toward reaching realistic goals.
- Perhaps, they can start something like a **'day care center'** where the rehabilitation workers, different parents of disabled children, other concerned parents in the community, or unemployed young persons can take turns caring for the disabled children for part of the day. This could be done on a volunteer basis. Or money to pay for caretakers could be raised by the community, either through donations, raffles, bake sales, musical events or other fund-raising activities.

It is important that the mother and family have rest periods from caring for their severely disabled child. Such rest periods can often make the difference between whether or not they can handle difficulties and keep treating the child in a loving, supportive way.

In some cases, it may be better to provide 'day care' in the child's own home. Again, the community may be able to provide either volunteers or paid care-providers.

Whatever the case, often **it is too much to expect the family of a severely disabled child to care adequately for the child, unless the community offers generous help and support.**



CARING FOR THE SEVERELY DISABLED CHILD

In deciding how to care for and work with the child who has a combination of severe disabilities, it is important to evaluate as best you can both her **disabilities** and **possibilities**. Especially in the very young child, this may not be easy. You must be ready to see new signs and change your ***evaluation***. This, in turn, may change your plan for working with the child, so as to best help her to develop whatever skills and responses are possible.

In evaluating and planning activities with the child, try to be realistic. Do not expect too much, because this can lead to disappointment. But at the same time, do not expect too little.

For example, a child with a serious physical disability who is also deaf and/or blind may appear to be mentally retarded simply because her ability to experience and respond to things around her is very limited. The child may, in fact, have a lot more ***mental*** capacity (or possibility) than she appears to have. It would be wrong not to look for ways of reaching, developing, and appreciating her mind. However, this may take great patience and creativeness by those caring for her.

SOME GOALS IN CARING FOR A SEVERELY AND MULTIPLY DISABLED CHILD :

1. To help her to be physically comfortable, clean, safe and well-fed.

2. To help her with ***positioning*** and exercise to prevent further deformity, and to make caring for her easier.

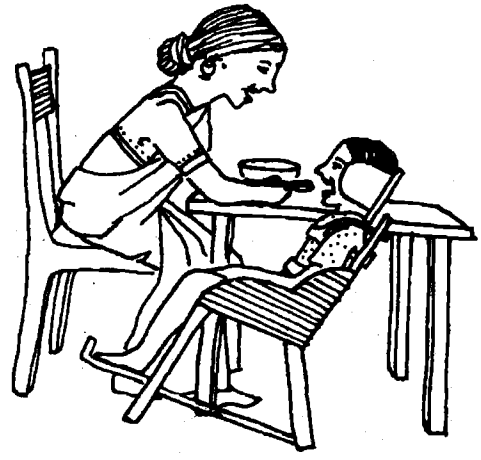
3. To help her learn whatever basic skills she can–in developing head and hand control, and in a way that her needs are met and her behavior is acceptable.

4. To make caring for the child easier and more enjoyable for those who are responsible for her.

Much of the information and suggestions in Chapters 35 and 36 on early stimulation and development may be helpful for the multiply disabled child. **Look for areas of development where the child seems to be most ready or to have possibilities. Then work out a plan of activity, stimulation, and rewards that will take the child forward one step at a time.** Some of the suggestions included in Chapter 41, "Ways to Improve Learning and Behavior," may also help. However, you will need to apply them with much patience and repetition.

To help meet the needs of the multiply disabled child, you will also find useful information in the chapters on the different disabilities that affect the child.

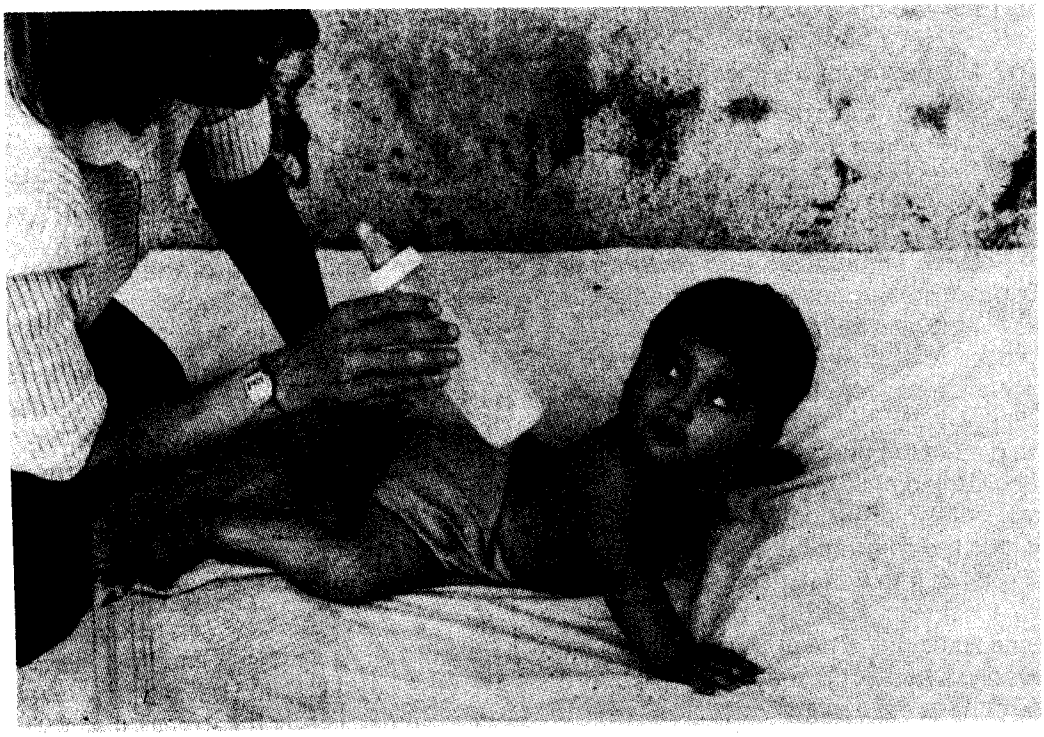
Special seating and positioning, discussed in Chapter 66, may help the child to have more control of her body. This can make feeding, basic communication, and other activities easier.



Special seating can help the severely disabled child by supporting him in a position where he has better control.



A child who is slower than most in learning to use her mind and body needs extra help. Learning to twist and to roll, and to lift on her arms and turn, are important early developmental steps. Here a rehab worker first helps 'loosen up' a child by slowly swinging her hips from side to side.



Then she encourages the child to lift up and turn to follow an object she wants.

***CAUTION* : Breast feeding is healthier than bottle feeding.** It is usually better to use a toy or rattle to draw the child's attention rather than a bottle.

CHAPTER 34

Lathyrism

Lathyrism is a disease that paralyses the lower limbs of a person for life, particularly men between the ages of 5 and 45 years. It is caused by eating large amounts of a *dal* pulse called **Lathyrus Satvius**, commonly known as **KHESARI DAL**. This pulse is also known by other names such as **MATRA, TEORA, BATRA, GHARAS, LANG, AKH, LAKHORI, LATRI DAL, LANKALU** and **KALI MATAR.**

Khesari dal is cultivated extensively in the Belan Canal area around the borders of Madhya Pradesh, Bihar and Uttar Pradesh as well as in West Bengal, Maharashtra, Karnataka, Mysore and Andhra Pradesh.

Khesari dal is a drought resistant rabi (winter) crop. Hence in times of famine it is regarded as a life saving crop, as it requires no irrigation facilities. It is sown in October – November and harvested in late February and early March. The disease appears from June onwards and the largest number of cases appear in July. Once the kharif (summer) crop is harvested in October–November, the number of cases decrease.

The plant is a legume with needle like elongated leaves and pink – purple flowers. The pods have seeds that are triangular in shape. Some varieties are pale grey in colour. The dehusked seeds resemble Tur dal. It is also more filling than wheat or Bengal gram.

Majority of the victims of lathyrism are landless labourers. In many communities people are aware of the ill – effects of eating Khesari dal. However, they have no choice but to eat it. *Khesari dal is given in lieu of wages.* It can neither be sold nor exchanged for any other grain or pulse because it fetches less. Studies have shown that thousands of people have been affected by this disease in Rewa and Satna districts of Madhya Pradesh alone. Often there is more than one member of the family who suffers from lathyrism.

The sale of Kesari Dal either by itself or mixed with any other pulse has been banned under the Prevention of Food Adultration Act. All the State governments have prohibited the use of this dal for human consumption. Bihar, Madhya Pradesh and West Bengal have yet to enact this legislation. (Central Health Education Bureau. Directorate General of Health Services).



The case of Bihari and his two sons is one such example.

Bihari, 62 years, old lives in a village on the outskirts of Allahabad, Uttar Pradesh. He and his family are very poor and have been eating Khesari Dal for a long time. Bihari worked as a labourer and earned this dal in lieu of wages. He has been suffering from Lathyrism. His two sons Ram Abhilakhi and Nikwa have also been suffering from lathyrism since their childhood.

No medical help was given to them in the early stages. The children were taken to the local *Vaids* local doctors and to temples in search of a cure. But nothing could be done to help them.



Nikwa is 35 years old and severely disabled. He has to crawl to move around. He earns his living by braiding rope. His father Bihari has to use a stick to move around as he goes about selling the rope made by his son. They earn Khesari dal as wages.

Ram Abhilakhi, the other son is 40 years old. He is a cobbler. He uses one stick to move around.



A folk verse shows how many communities are dependent on this crop for their basic needs.

MATRA KI ROTI MATRA KI DAL,
MATRA KI PATI RAKHAN HAR.

(Matra as bread and matra as dal
Matra indeed is the guardian of all).

THE WARNING SIGN

Muscle spasms is the earliest sign of lathyrism . Usually a few days before the onset of actual paralysis, a person feels a sudden and severe pain in the calf muscles or in the muscles at the back of the thighs, at night, after the person has been resting for some time and the legs are stretched. The pain is accompanied by spasms. The calf muscles turn into the shape of a ball or a lump. The person feels a similar contraction in the muscles at the back of the thighs. There is also a downward clenching of toes and feet. The contraction remains till the spasm passes, either with massage or by itself. This takes about 10 to 15 minutes. Sometimes the spasms are mild. There may also be mild or severe pain in the knee and ankle joints.

A week or two later, *some of the persons* so affected develop the disease. The spasm is repeated occasionally and stops after many months only after the person develops a full fledged condition.

However some of them do not develop the disease. They do not have the typical signs of physical disability. There is stiffness in the limbs and a slight bending of the knees and some awkwardness or difficulty in walking or running downhill.

How the disease starts

The onset of the disease may be of three types :

1. **Acute onset** – In more than half the patients the disease starts this way:

   While working the person falls, and cannot stretch his legs. The knee joints bend, there is heaviness in the limbs and diffculty in walking. The stiffness in the muscles goes on increasing till the person is unable to walk. It takes from ten days to a month for him to improve. After this period of complete disability, the paralysis gradually sets in. **Women generally do not have an acute onset.**

2. **Sub – acute onset** – This usually happens about 15 days after the muscle spasm. The attack is brought on by a sudden physical effort,for example: jumping across a stream or 'nullah', chasing cattle or getting out of bed after sleep. The person falls down. He rises to walk but finds in a very short time that he cannot do so easily. There is usually no pain, yet in a few hours the person feels a stiffness in the lower limbs which increases slowly till the walk becomes jerky and awkward.

   It may take from one month to one year before the person progresses into any of the stages of the disease. **Women are more prone to have a sub – acute onset.**

3. **Insidious onset** (when the disease creeps in without the person being aware of it). In this kind of onset the muscle spasm is not present. Pain, if present is mild and dull. This dull aching of the limbs may continue for two to three months. There is a stiffness and heaviness in the limbs and a slow developing of awkwardness while walking. **Women do not generally progress any further** but in men this may increase and in about six months they may need one or two sticks to walk. Some of these person may go into the final stage of paralysis.

Jabar Ali returned home one day with fever after he had spent the day in the fields watering the crops. The fever was accompanied by backache and severe pain in the waist. Next day he found he could not walk. In a short while he developed the disease. Today he moves around in a wheel chair. He also needs 2 sticks to balance himself while walking, with great difficulty.

Jabar Ali was a farmer. He looked after his land and supported his family of four children. Today he has had to change his trade because of his disability. He makes and sells *bidis* with the help of his now grown son. Apart from the support and medical facilities he receives from Viklang Kendra, Jabar also gets a monthly pension from the government.



STAGES OF LATHYRISM



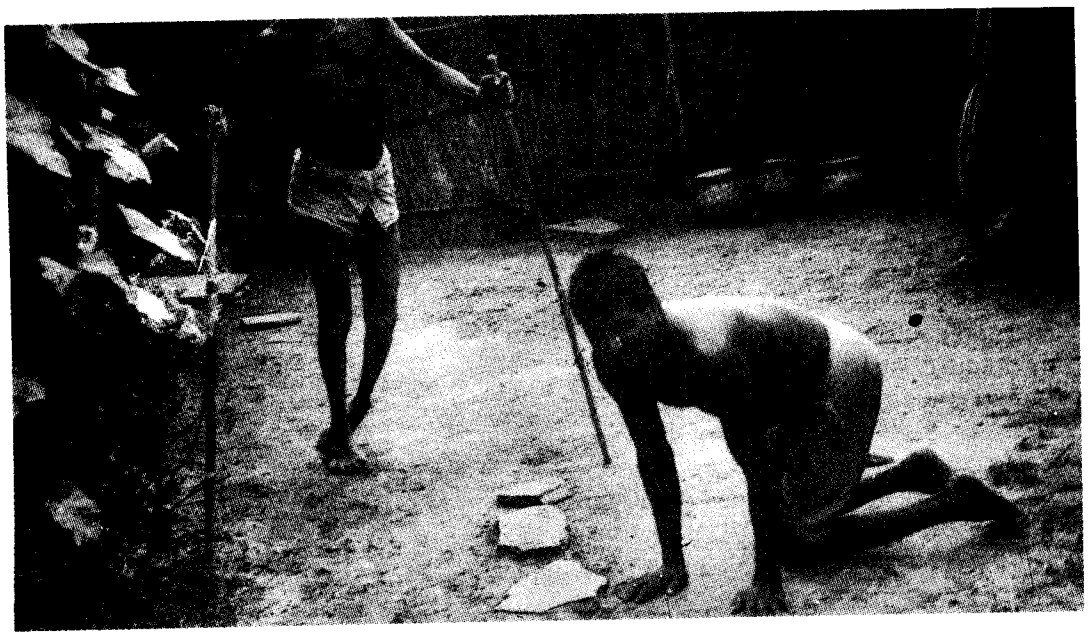
First stage–The largest number of people are found in this stage of the disease. It is characterised by a typical type of walking. The person walks on his toes with short steps and jerky movements and with knees slightly bent and ankles extended. The walk is criss–crossed. The waist is sometimes tilted and the head sways from side to side. The person can manage to walk without a stick.He may remain in this stage for the rest of his life or pass on to the next stage. **This is the No Stick** stage.



Second stage – It may take from one month to ten years to reach the stage when he is unable to walk without a stick. There is increasing bending at the knee joints. He also needs to raise his heels while walking. This is called the **one stick** stage.

Third stage – It is very common for a person to go directly to this stage. The stiffness of the leg muscles is severe and there is a marked tilting of the pelvis (hips) sideways, to maintain balance while walking. The person therefore needs **two sticks** to walk.

Fourth stage – This is the final stage and by this time the person is unable to walk upright. The legs give way at the knee joints. The person now crawls or shuffles along by putting his weight on his hands.



What to Do

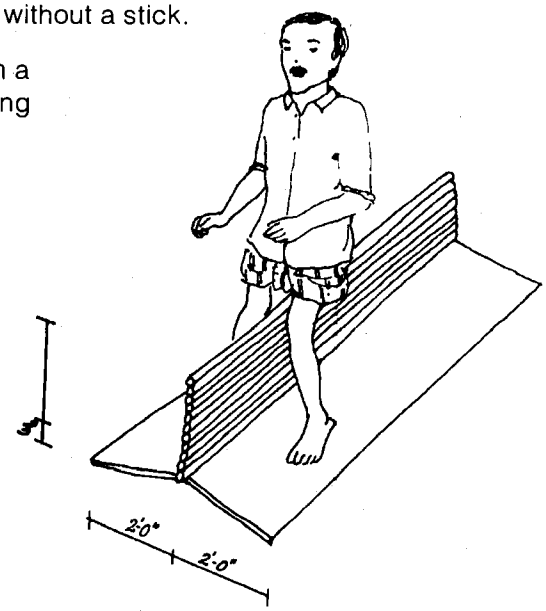
Proper and timely management can sometimes help in arresting the disease or even reversing it from **one stick stage to no stick stage.** However this reversal is difficult when the person has reached beyond this stage.

Regular massage with oil and personal efforts to stretch the muscles is extremely important. For example, Suresh walks on his toes because he is unable to put his foot flat on the ground while walking. He is taught by the therapist to try and put his whole foot on the ground so that slowly his muscles will relax and he is able to walk with his foot flat on the ground and manage to do so without a stick.

For relaxing the stiffness of the muscles, exercises for the trunk and upper extremities and abdominal (stomach) muscles are very important. These exercises can be taught by the therapist to any family member. Stiffness of the stomach muscles and the tendon of the calf muscles do not usually respond to short term exercises. But if they are continued over a long period of time, there is gradual improvement and the person can go back to the stage where he can manage without a stick.

For improving the walk parallel bars with a divider in the middle at knee level and sloping sides are very helpful.

Fix a solid divider made of bamboo or any other material in the middle of a board (you can even fix it on the ground) with a slope on either side of the board. The board is two feet wide with a three inch slope on each side of the divider. To prevent the person's knee from getting injured a padding is put on the knees or on the divider itself. (Viklang Kendra, Allahabad, has devised and used this method for correcting the walk very effedtively with many people suffering from lathyrism)



In acute cases of lathyrism a wheel chair may be given. Suitable vocational training can also be effectively used to reduce spasticity.

PREVENTION

There is no cure for lathyrism. Once affected, the condition is permanent and the person suffers from its ill – effects all his life

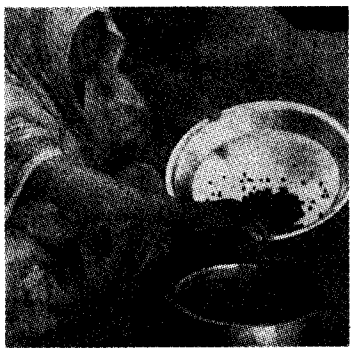
If the person stops eating the Khesari Dal after the first muscle spasm, the disease is arrested and he does not develop Lathyrism in its full form. This also applies to persons in the early stages of the development of this disease.

In many communities this crop is consumed in the form of *'rotis'* made from Khesari dal flour and accompanied by perhaps some other dal and a white raddish or other vegetables when available. Some people also eat it in the form of porridge. Green vegetables, milk, meat or eggs are rarely eaten by these people.

Khesari dal has a poisonous substance called BOAA which cause *Lathyrism*. This dal can be made safe for consumption by this simple method and can be done at home. After dehusking the pulse follow this simple method.



Wash In Cold Water



Add the dal after boiling water



and soak the dal for 2 hours in hot water (Do Not Boil)



Drain and wash in cold water



Dry in the Sun



It is now safe to use

Poisonous Khesari dal can be made safe by the above simple method and can be done at home. This method will remove most of the poisonous substances from the dal.

Khesari dal should not comprise of more than a quarter of the cereals consumed per day and should be accompanied by leafy vegetables.

Here is a meal pattern recommended *(National Institute of Nutrition, Hyderabad.)*

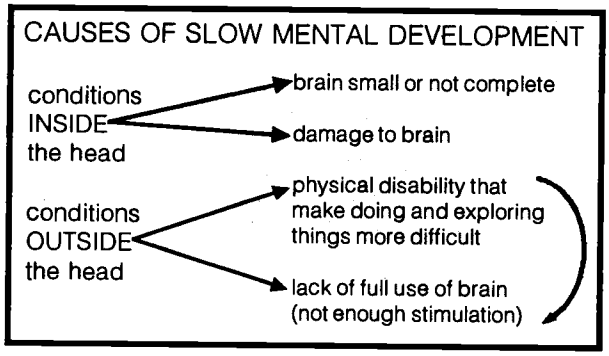
- 3/4 wheat or barley
- 1/4 Bengal gram dal and Khesari dal
- Tur dal
- Muli (white raddish)
- Green leafy vegetables (or the cooked Muli leaves)
- Groundnuts or milk.

Note: It is now possible to grow selected varieties of this pulse which are low in toxins (0.1 percent). These varieties can be obtained from the Pulse Co-ordinator, Indian Agricultural Research Institute, New Delhi, through the help of the local agricultural officers in your area. (Central Health Education Bureau, New Delhi).

CHAPTER 35

Child Development and Developmental Delay

In Chapter 32 we discussed some of the primary causes of *'mental retardation'*. Mostly we looked at disabilities that come from **inside a child's head** – conditions where the brain has been damaged, is too small, or for other reasons is not able to work as quickly as other children's brains.

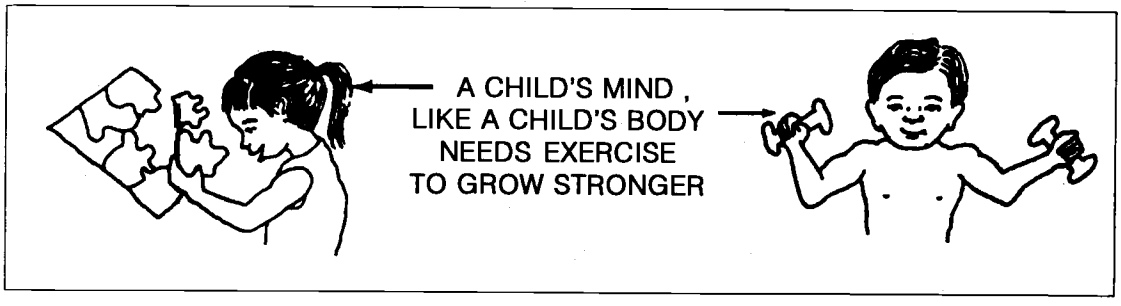


In this chapter we see how a child's early development also depends on factors **outside the child's head** – on the opportunities a child has to use his senses, mind, and body to learn about the things and people around him. We look at the stages or steps of normal child development, and at ways we can help or 'stimulate' a child to learn and do things more quickly. Our concern is not only to help children who are 'mentally retarded', but those whose development is slow, or 'delayed', for whatever reason.

Usually children whose minds are slow to develop are also slow in learning to use their bodies. They begin later than other children to lift their heads, roll, sit, use their hands, stand, walk, and do other things. **They are physically delayed because of their delayed mental development.**

In other children the opposite is true. Their minds are basically complete or undamaged, but **certain physical disabilities make it harder and slower for them to develop the use of their minds.**

For example, a child who is born deaf but whose brain is normal will have difficulty understanding what people say, and in learning to speak. As a result, she is often left out of exchange of ideas and information. Because language is so important for the full development of mind, in some ways she may seem 'mentally slow' for her age. However, if the child is taught to communicate her wishes and thoughts through 'sign language' at the age when other children learn to speak, her thinking power (intelligence) will often develop normally (see Chapter 31).

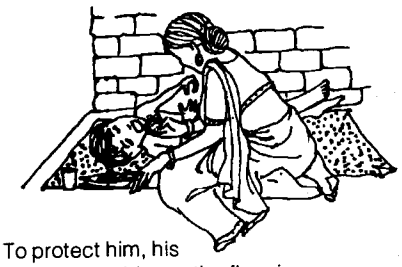


On the next page is a true story that shows how a severe physical disability can lead to slow mental development, and how a family found way to help their child develop more fully.

AMIT'S STORY

(CP)

Amit had a difficult birth. He was born blue and limp. He did not start breathing for about 3 minutes. As a result, he developed severe cerebral palsy. His body became stiff and made strange movements that he could not control. His head often twisted to one side and he had trouble swallowing.



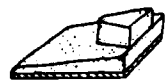
To protect him, his mother kept him on the floor in a corner.

Amit's mother loved him and cared for him as a best she could. But as the years went by, he did not gain any control of his body. His mother kept him on the floor in a corner so that he would not hurt himself. He spent most of his young life lying on his back, legs stiffly crossed like scissors, head pressed back. looking up at the roof and the mud brick walls. By age 3 he had learned to speak a few words, but with great difficulty. By age 6 he spoke only a little more. He cried a lot, had temper tantrums, and did not control his ***bowels*** or ***bladder***. In many ways he remained like a baby. A visiting nurse called him 'retarded. Still lying alone in the corner, Amit grew increasingly withdrawn. At age seven – he asked her for a gun to kill himself.

Soon after this, Amit's mother and his older sister took him to a team of village ***'rehabilitation'*** workers in a neighboring village. The workers realized that he would probably never have much control of his hands and legs. But he desperately needed to communicate more with other people and see what was going on around him, to be included in the life of his family and village. But how could he do this lying on his back? His mother had tried many times to sit him in a chair, but his body would stiffen and he would fall off or cry.



The village workers helped Amit's family make a special chair for him, with a cushion and hip strap to help him sit in a good position. They taught his mother and sister how to help him sit in a way that would keep his body from stiffening so much.



SPECIAL CUSHION (SEE P. 735)



Later, they added wheels to the chair. Amit's sister learned how to position him in his new chair

With his new chair, Amit was able to sit and watch everything that was going on around him. He was excited and began to take more interest in things. He could also sit at the table and eat with the family (although his mother still had to feed him). Everyone talked to him and soon he began to talk more. Although his words were difficult to understand, he tried very hard. In time, he spoke a little more clearly. He also began to tell people when he had to use his toilet. He discovered he was no longer a baby, and did not want to be treated as one.



Every day Amit's sister and brother went to school. One day Amit begged to go too, and they pushed him there in his chair. Soon he went every day, and began to learn to read. Amit had begun to develop more control of his head. The village workers helped the teacher make a book holder attached to Amit's chair, and a head band with a wire arm so that he could turn the pages.



A happier and fuller life had begun for Amit.

Amit's story shows how development of the body, mind, and senses all influence each other. Amit was slow to develop mentally because he did nothing but lie on his back in a corner. His mind did not have the 'stimulation' (activity, exercise, and excitement) it needed to grow strong. He had almost no control of his body movements. However, his eyes and ears were good. When at last his body was placed so he could see and experience more of the world around him, and relate more to other people, his mind developed quickly. With a little help and imagination, he learned to do many things that he and his family never dreamed he could.

We saw how Amit's physical disability slowed down his mental development. Similarly, a child who is mentally slow is often delayed in physical development. Development of body and mind are closely linked. After all, the mind directs the body, yet depends on the body's 5 senses (sight, hearing, touch, taste, and smell) for its knowledge of people and things. Therefore :



Amit's sister helps position him in his new chair.

PHYSICAL DISABILITY —can lead to→ MENTAL DISABILITY

MENTAL DISABILITY —can lead to→ PHYSICAL DISABILITY

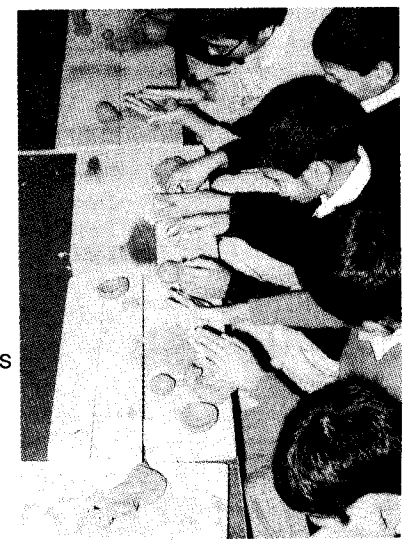
UNLESS special care is taken to help the child develop BOTH BODY AND MIND as fully as possible.

Each child, of course, has his or her own **special needs**. Parents and rehabilitation workers can try to figure out and meet these needs. (An example is Amit's need for special ***positioning*** so that he can see and do things better).

But **all children** have the same **basic needs.** They need love, nutritious food and shelter. And they need the chance to explore their own bodies and the world around them as fully as they can.

EARLY STIMULATION

'Stimulation' means giving a child a variety of opportunities to experience, explore and play with things around her. It involves body movement and the use of all the senses– especially seeing, hear, and touching.



Early stimulation is necessary for the healthy growth of every child's body and mind. For the non-disabled child, stimulation often comes naturally and easily, through interaction with other people and things. But it is often more difficult for the disabled child to experience and explore the world around him. For his mind and body to develop as early and fully as possible, he will need extra care and special activities that provide easy and enjoyable ways to learn.

The younger the child is when a stimulation program begins, the less retarded or delayed he will be when he is older.

NORMAL CHILD DEVELOPMENT

In order to know how well a child is developing and in which areas she may need special help, we can compare her development with that of other children.

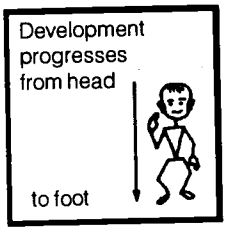
An understanding of normal child development **can guide us in planning activities that will help the disabled child progress.**



A child's abilities develop in a particular order, one upon the other, like building blocks.

Every child develops in 3 main areas : **physical** (body), which includes gross and fine motor skills and vision; **mental** (mind) which include hearing, language, comprehension and concept development and **personal –social** development which include self–help and communication skills. In each area, she develops skills step by step in a certain order. During the first year of life, normally a baby gains more and more control of her body.

Body control develops progressively from the head down:



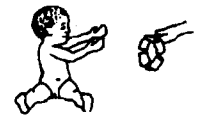
first, head and eye control



next, arm, and some hand control



then trunk (body) control, sitting, and balancing



and finally leg control



Before she can begin to walk, a baby needs to go through a series of developmental stages, or 'levels'. First she has to be able to hold up her head and see what is around her. This encourages her to use her arms and hands so that she can then learn to lift herself to sit. While sitting, she begins to reach, lean, and twist. All this helps her to develop balance and walking. Normally, the stimulation that a child needs to advance through these stages comes from ordinary day–to–day interaction with people and things.

However, a child who has a disability may need special help to keep progressing. Notice that in the above example, the child's ability to **see** makes her **see things and want to reach for things and explore.** Seeing stimulates her to try to learn and do more. If a child cannot see, this basic part of early stimulation is lacking. To prevent her falling behind, we must look for other ways to encourage her to learn and do things. We can do this through **touch** and **sound**, adapting the type of stimulation we use to the child's particular stage of development. For example, **if a baby cannot see:**

From the beginning we should hold her and speak to her a lot. Help her to reach out to touch and feel different things.



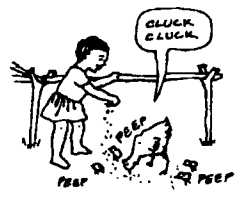
Later, we can encourage her to lift and turn her head, and then reach out, toward different sounds.



When she begins to sit, again we can help her to recognize different sounds and reach toward them



When she begins to walk we can help her find her way with guide poles, and in other ways.



For more ways to help a child who cannot see well, see Chapter 30.

It is important for parents to realize that a child develops control and use of her body in a certain order :

HEAD CONTROL→*TRUNK* CONTROL (SITTING AND BALANCE)→STANDING AND WALKING

This is true even for an older child. Often parents of an older child who is delayed will try to help her learn more advanced skills (which other children her age are learning) before she is ready. This often leads to disappointment and frustration both for parents and child.

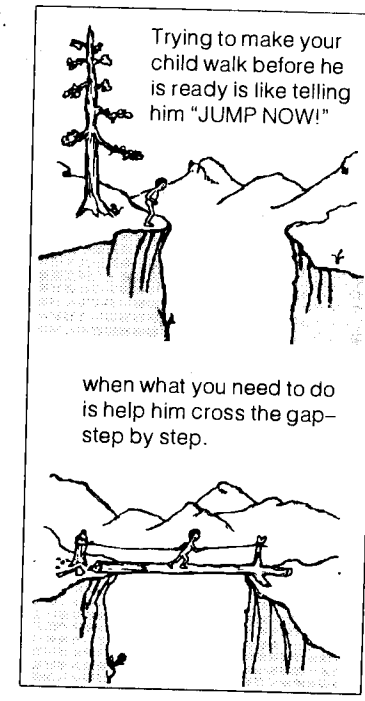
For example, Nina is a 3–year–old girl with cerebral palsy. She still has trouble holding up her head or sitting without falling over.



However, her mother is sure she is 'almost ready to walk'. Several times each day she holds Nina in a standing position and moves her forward, so that her feet take stiff, jerky steps on tiptoe. Her mother does not know that this stepping is an 'early reflex' normally only seen in young babies (see p. 381). It means that in some ways Nina's development is still at the level of a 1–to 3–month–old baby. She is not yet ready to walk. Making her 'take steps' will only keep active the early reflex which she needs to lose in order to learn to really walk.



'stepping reflex' in a 1–month–old baby



We must help Nina's mother realize that Nina first needs help with other important developmental steps before she will be ready to learn to walk. To help her develop further, her mother will need to:

1. Figure out what developmental age or stage the child is at.
2. Decide what are the next steps forward, so that the child can build new skills on the ones she has now, **in the same order in which a normal child develops.**

To do these things, Nina's mother should first observe the child carefully. In each area of development, she notes the different things Nina **can do**, the things she **cannot do yet,** and the things she is **just beginning or trying to do** but still has trouble with. Next, her mother compares what Nina can and cannot do with what other children Nina's age can do. She can then decide at what level her child is at in each area of development, and what are the next steps to work toward.

THE CHART ON NORMAL CHILD DEVELOPMENT

The chart on the next 2 pages shows some of the steps or 'milestones' of normal child development. You can use it to figure out where a child is in her development, and to plan the next steps that she needs help with.

CAUTION: The development chart shows the average ages when children begin to do things. But **the ages at which normal children develop different skills vary greatly.** Just because a child has not developed certain skills by the ages shows does not mean he is backward or has a problem. Be sure to **look at the whole child.**

Name : _____

Birth date : _____

Date : _____

EVALUATION OF A CHILD'S LEVEL OF *PHYSICAL* DEVELOPMENT

RECORD SHEET 6 (page 1)

Note : Although on these guides physical and mental skills are separated, the two are often closely interrelated. These charts show roughly the average age that a normal child develops different skills. But there is great variation within what is normal.

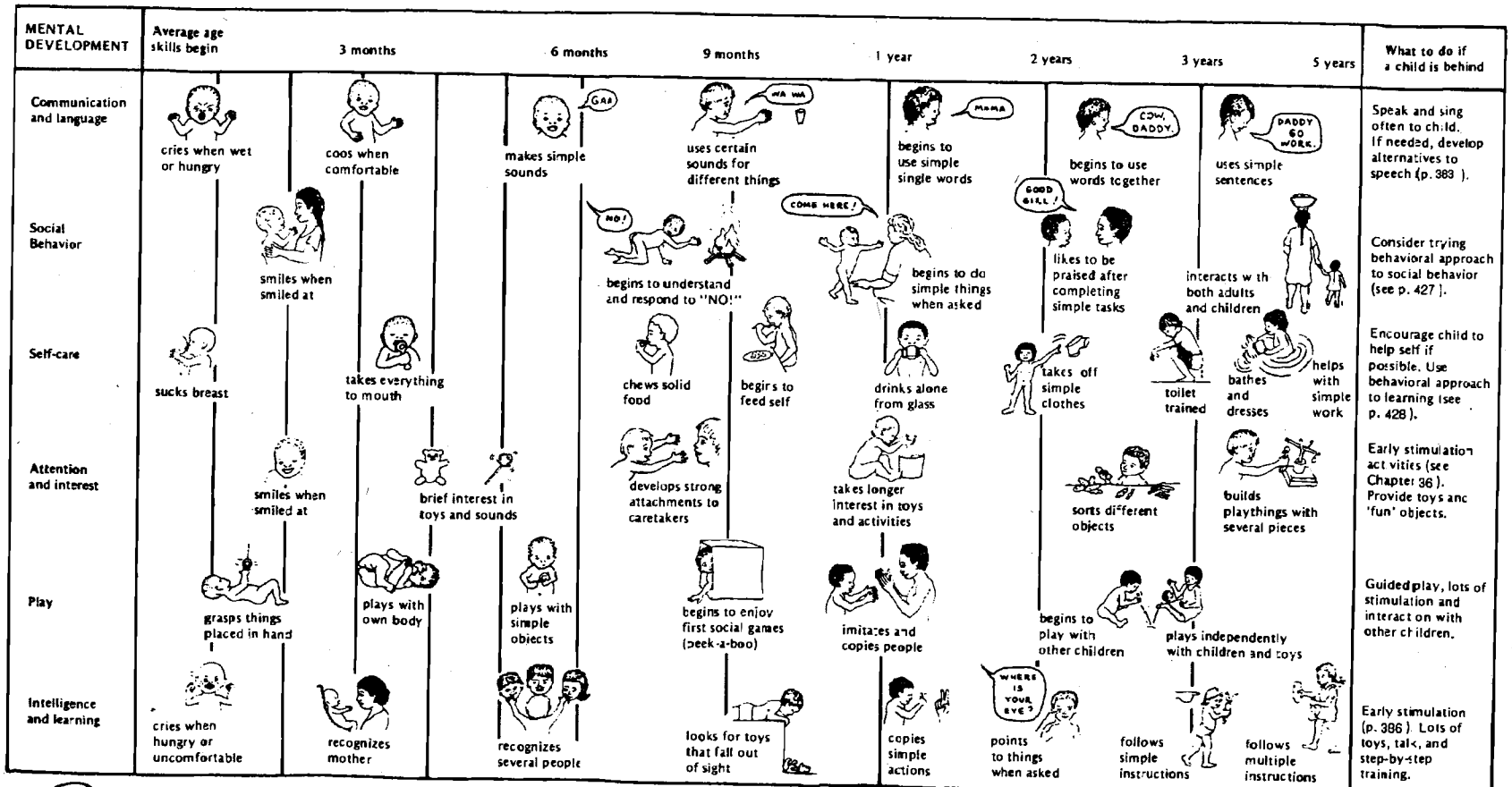
PHYSICAL DEVELOPMENT	Average age skills begin	3 months	6 months	9 months	1 year	2 years	3 years	5 years	What to do if a child is behind
Head and trunk control		holds head up briefly; holds head up high and well	holds up head and shoulders; turns head and shifts weight	holds head up well when lifted	moves and holds head easily in all directions				Activities to improve head and trunk control (see p. 372..
Rolling		rolls belly to back; rolls back to belly		rolls over and over easily in play					Activities to develop rolling and twisting (see p. 374).
Sitting		sits with some support.	sits with hand support; begins to sit without support	sits well without support	twists and moves easily while sitting				Work on sitting. Special seating if needed (p. 378).
Crawling and walking			scoots or crawls	pulls to standing	takes steps; walks; runs		can walk on tiptoe and on heels; walks easily backward; hops on one foot		Activities to improve balance (see p. 376).
Arm and hand control	grips finger put into hand	begins to reach towards objects	reaches and grasps with whole hands; passes object from one hand to other	grasps with thumb and forefinger		easily moves fingers back and forth from nose to moving object	throws and catches ball		Eye-hand activities. Use toys and games to devolop hand and finger control (see p. 375).
Seeing	follows close object into hand	enjoys bright colors/shapes	recognizes different faces	eyes focus on far object	looks at small things/pictures		Sees small shapes clearly at 6 meters (see p. 453 for test)		Have eyes checked (see p. 546). If poor, see Chapter 30.
Hearing	moves or cries at a loud noise	turns head to sounds; respond to mother's voice	enjoys rhythmic music	understands simple words	hears clearly and understands most simple language				Have hearing chaecked. If poor, See Chapter 31.

Name: _____

Birth date: _____

Date: _____

EVALUATION OF A CHILD'S LEVEL OF *MENTAL AND SOCIAL* DEVELOPMENT



Put a (circle) around the level of development that the child is now at in each area.

Put a [square] around the skill to the right of the one you circled, and focus training on that skill.

If the child has reached an age and has not mastered the corresponding level of skill, special training may be needed.

RECORD SHEET 6 (page 2)

How to use the Child Development Chart

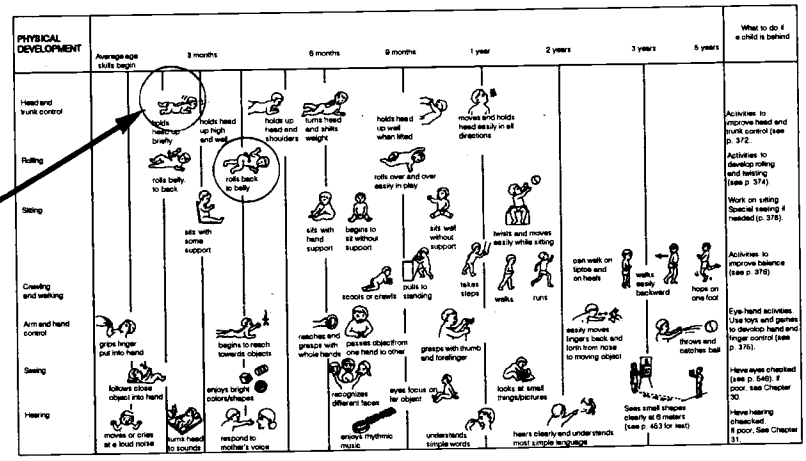
The chart on pages 360 and 361 can be used to:

1. find and record a child's developmental level.
2. select the skill and plan the next developmental steps or activities with which we can help the child,
3. and record in which areas the child is progressing, and how much.
4. Re–assess, evaluate progress before planning the next step.

Let us suppose that a village health worker wants to help Nina's mother figure out what she needs to do next to help her 3–year–old daughter develop early abilities. Together they look at the chart.

First they put a circle around each of the things that Nina can do. Since she still has trouble holding her head up, they put a circle here.

Nina needs help to roll from her belly to her back, so they put a circle that goes part way around 'rolls belly to back'.



After they circle Nina's level in each area of development, they can see that in her general body movements and control, Nina is still at the level of a 2 to 4 month – old baby. Her hand control is at about 6 months. Her seeing and hearing seem about normal, and her mental development is at about 2 years.

Then they put a square around the next developmental step after each circle. **The squares show which developmental steps Nina now needs help with.** Because Nina's poor head control is holding her back in other areas, they decide to work mostly with this (see p. 372), and also to help her with rolling and twisting her body (see p. 374). perhaps they can begin to work with sitting and crawling, but probably she will not progress much with these until she gets better head control. The use of her hands is still somewhat behind for her age, but this may partly be because of her poor head control. So they decide to have her sit for short periods each day in a special seat. With her head supported in a good position, they can give her games and things to do to help her develop better use of her hands. But, they are careful **not** to keep her head supported for long, because that will not help her to learn to support it herself. Also, they are careful to provide only the least amount of support needed to give her better control of other parts of her body. They will reduce the support as her control improves.



Because Nina's eyes, ears, mind, and speech seem to be developing fairly well, these will probably be what she learns to use best as she grows older. Therefore, Her parents decide to do all they can to help her improve these skills. They use pictures, songs, stories, play, and a lot of stimulation to help her develop her mind. But they try to remember that she is still only 3 years old. They must not push her too much. Sometimes it is better to help her gain skill and confidence in only 1 or 2 areas at a time.

To use the Child Development Chart for recording a child's progress, every month or two you can add new circles to the chart. Use a different colored ink each time, and mark the date in the same color. Then add new squares to determine the developmental steps that are next in line. (See p. 51)

To implement the program after identifying the exact areas in which the child needs training, the village health worker selects the skill to be taught in consultation with the mother or the person who is going to train the child. She explains and demonstrates the activities for each skill. After specified duration of time, she evaluates the progress made in each skill. If the child is able to perform the skill without help, she selects a new skill from the child development chart. If not the training of the same skill continues.

Here is an example of a Record Sheet for PROGRAMME PLANNING and EVALUATION of a child's progress.

Remember that each skill that is selected has to be divided into small steps.

Nina can also be helped to hold her head erect when placed on her stomach on the ground.

Materials that you can use : toy and a round pillow.

1. Keep the pillow under her arms and chest. Hold a colourful toy in front of her and let her look at it.
2. Place her on her stomach without the pillow. Rest her elbows on the floor. With your hands guide her to lift her hand and look up. Gradually reduce support.

RECORD SHEET FOR PLANNING AND EVALUATION OF CHILD'S PROGRESS

DATE : Begining of Training : .....

Evaluation : .....

NAME :

Person Responsible : *Field Worker*

SKILL	ACTIVITIES	DURATION	WITHOUT HELP HELP	WITH LITTLE HELP	WITH LOTS OF HELP	REMARKS
Holds up head and shoulders	Described on page (372)	One month	✓			Independent
Rolls back to belly	described on page (374)	One month		✓		Needs practice
Begins to reach towards objects	described on page (375)	One month		✓		needs a few more days of training

EARLY STIMULATION

Stimulation means giving a child a variety of opportunities to experience, explore, and play with things around her. It involves body movements and the use of all the senses–especially seeing, hearing and touching.

Early stimulation is necessary for the healthy growth of every child's body and mind. For the non–disabled child, stimulation often comes naturally and easily, through interaction with other people and things. But it is often more difficult for the disabled child experience and explore the world around him. For his mind and body to develop as early and fully as possible, he will need extra care and special activities that provide easy and enjoyable ways to learn.

The younger the child is when a stimulation program begins, the less retarded or delayed he will be when he is older.

The Need For Early Stimulation

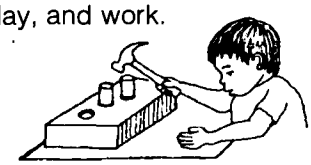
The parents and family are the key to the development and early learning of any child. Children who are developmentally slow need the same stimulation (talking to them, music, games, adventure, and love) that any child needs. But they need more. They need more help and repeated activities to use their minds and their bodies.

When a child is delayed, he needs stimulation and activities to help develop all areas of his body and mind.

AREAS OF A CHILD'S DEVELOPMENT THAT CAN BE HELPED THROUGH EARLY STIMULATION AND LEARNING ACTIVITIES

1. **Movement, body control, strength, and balance:** these will help the child move about, do things, play, and work.





2. **Use of the hands:** increased hand control, and coordination of the hands with what the child sees, allows the child to develop many skills.

3. **The senses:** especially seeing, hearing and feeling. These will help the child recognize and respond to her world.



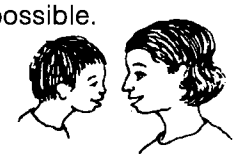






4. **Communication:** listening, understanding what is said, and learning to speak, or to communicate in whatever way is possible.

5. **Interaction with other people:** smiling, playing, behaving appropriately, and learning to 'get along' with others.





6. **Basic activities for daily living:** eating, drinking, dressing, and control of bowel and bladder (peeing and shitting). These 'self–care' skills help the child become more independent.

7. **Observing, thinking, and doing:** to learn how to make thoughtful, intelligent decisions.



The goals of an early stimulation program are to help the child become as able, self–sufficient, happy, and kind as possible.

STEPS IN DESIGNING A PROGRAM OF SPECIAL LEARNING AND EARLY STIMULATION

First: Observe the child closely to evaluate what he can and cannot do in each developmental area.

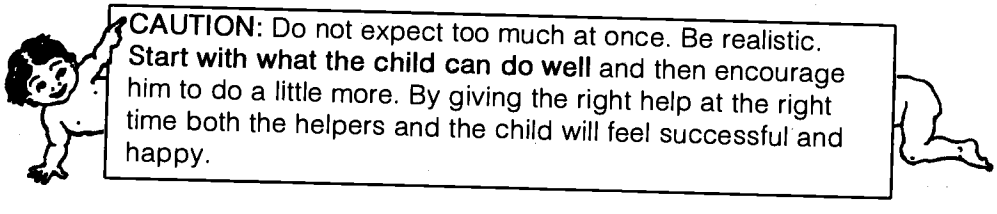
Second: Notice what things he is just beginning to do or still has difficulty with.

Third: Decide what new skill to teach or action to encourage that will help the child build on the skills he already has.

Fourth: Divide each new skill into small steps: activities the child can learn in a day or two, and then go on to the next step.

Fifth: Provide sufficient practice before you take a new skill for teaching.

Sixth: Plan activities that give opportunity to practice the new skill he has learnt.



CAUTION: Do not expect too much at once. Be realistic. **Start with what the child can do well** and then encourage him to do a little more. By giving the right help at the right time both the helpers and the child will feel successful and happy.

SUGGESTIONS FOR DOING LEARNING ACTIVITIES WITH ANY CHILD (DELAYED OR NOT)

Be patient and observant. Children do not learn all the time; sometimes they need to rest. When they are rested, they will begin to progress again. Observe the child closely. Try to understand how she thinks, what she knows, and how she uses her new skills. You will then learn how to help her practice and improve those skills. When talking with the child, give her time to answer your questions. Take turns speaking. Remember that practice and repetition are important.

Be orderly and consistent. Plan special activities to progress naturally from one skill to the next. Try to play with the child at about the same time each day, and to put his toys, tools, clothes, and so on, in the same place. Stay with one style of teaching, loving, and behavior development (if it works!). Respond in a similar way each time to the child's actions and needs. This will help him to understand and to feel more confident and secure.

Use variety. While repetition is important, so is variety! Change the activities a little every day, so that the child and her helpers do not get bored. Do things in different ways, and in various places inside and outside of the house. Take the child to the market, fields, and the river. Give her a lot of things to do.

Be expressive. Use your face and your tone of voice to show your feelings and thoughts. For example: saying **GOOD!** with a grim face or saying **NO!** with a smile will not give the correct message to the child. Praise and encourage the child often. Speak clearly and simply (but do not use 'baby talk'). Praise and encourage the child often.

Have a good time! Look for ways to turn all activities into **games** that both the child and you enjoy.

Be practical. Whenever possible choose skills and activities that will help the child become more independent and be able to do more, for himself and for others. To help prepare the child for greater independence, do not overprotect him.

Be confident. All children will respond in some way to care, attention, and love. With your help, a child who is delayed can become more able and independent.

A special learning program, if well-planned and carefully done, can help a delayed child progress much more than she would without help.

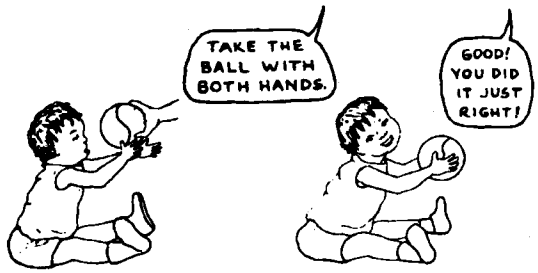
GENERAL GUIDELINES FOR HELPING A CHILD'S DEVELOPMENT

How a family member or rehabilitation worker relates to a child when trying to teach her new skills can make a big difference in her whole development. It can affect how fast or well she learns the new skill. More importantly, it can influence the child's confidence, behavior, and readiness to learn.

There are a few methods that you can use to help a child gain a better **understanding of her own body, prepare her for learning, language,** and **help her relate to other persons in a friendly, cooperative way.**

These guidelines are especially helpful when doing early learning activities with children who are developmentally delayed:

1. **Praise the child a lot.** Praise him, hug him lovingly, or give him a little prize when he does something well (or when he makes a good effort).



Explanation

Praising success works much better (and is much kinder) than scolding or punishing failure. When the child tries to do something and fails, it is best to ignore it or simply say something like: "Let us do it again."

***CAUTION* : Avoid giving sweets or food as prizes –especially if the child is fat (see box on p. 416).**

2. **Talk a lot to the child.** Using clear, simple words, say everything that you do with him.



Explanation

A child listens to and begins to learn language long before he begins to speak. Although it may seem as though he does not understand or respond, still talk to him a lot. If you think he does not hear, talk to him but also use 'sign language'. Make sure he looks at you as you speak. (See p. 383 to 384.)

3. When you are helping a child learn a new skill, **guide her movements with your hands.**

For example, to teach a child to bring her hands to her mouth (or to eat by herself) you can:

help her put her finger in a food she enjoys.

and then guide her hand to put her finger in her mouth.

After the child has learned to do this, let her do it by herself.



Explanation

It usually works better to gently guide the child than to tell her how to do something. If she tries to do something but has difficulty, guiding her hands so that she is successful will make her a lot more eager to learn the skill than if you say "NO–do it like this!"

4. **Use a mirror** to help the child learn about his body to use his hands and for activities such as brushing teeth, combing, buttoning etc.



Explanation

The mirror helps the child see and recognize parts of his body. It is especially useful for children who have difficulty relating to different parts of their body of knowing where they are. (this can happen in some forms of mental retardation, cerebral palsy, spinal cord injury, and spina bifida.)

5. **Use imitation (copying).** To teach a new action or skill, do something first and encourage the child to copy you. Turn it into a game. Involve siblings or other children in the game. They will be good models to follow.



Explanation

Many mentally handicapped children (especially those with Down syndrome) love to copy or imitate the actions of others. This is good way to teach many things, from physical activities to sounds and words.

6. **Encourage the child to reach out or go for what he wants.** Allow the child to make efforts to ask for things.

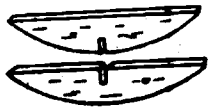


When it gets too easy, put obstacles in the way – but do not make them too difficult.

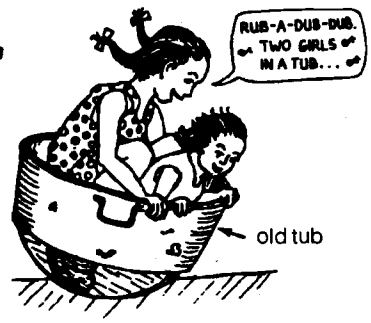
Explanation

Even at early stages of development, it is a mistake to always place in his hands what a child wants. Instead, use the child's desire as a chance to have him use his developing body skills and language skills to get what he wants–by reaching, twisting, rising, creeping, or whatever he is learning
to do.

7. **Make learning fun.** Always look for ways to turn learning activities into play.



2 pieces of wood notched to fit together crosswise



Explanation

Children learn best and cooperate more when they enjoy and are excited by what they are doing. **Keep doing an activity as long as it is fun for the child. As soon as it stops being fun, stop the activity for a while, or change it in some way, to put new adventure and excitement into it.** Sometimes children persist on playing with certain things or toys for a long time or always. They refuse to play with other things. Encourage them to play with a variety of material.

8. **Let the child do as much as she can for herself. Help her only as much as is needed.**

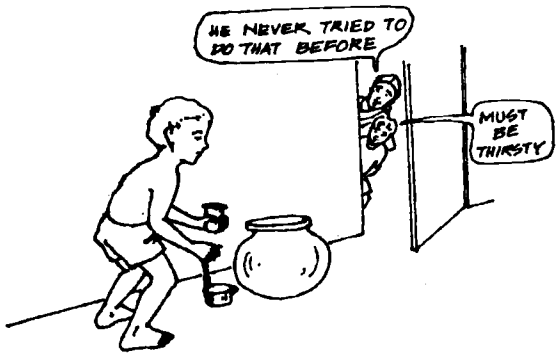
   For example, if child has trouble putting on clothes because of *spasticity,* help by bending her shoulders and back forward, but let her pull on her clothes herself.



Explanation

This is the "Golden Rule of Rehabilitation." When a child has trouble doing something or seems slow or clumsy at it, parents often want to 'help' by doing it for her. However, for the child's development, it will help her more to let her do it herself, at her own pace – providing encouragement but assisting only in ways that let her do more for herself.

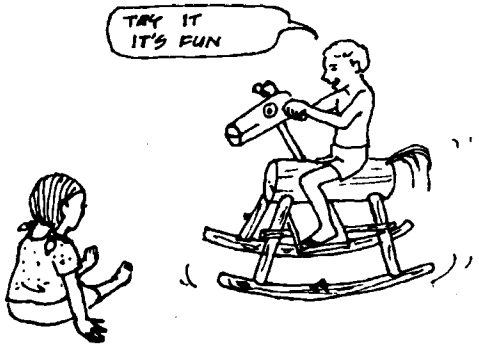
10. **The child often learns best when no teacher is present.**



Explanation

Children often try hardest when they want something a lot, and no one is there to help. Teaching is important, but so is giving the child a chance to explore, test his own limits, and do things for and by himself.

10. **Get older brothers and sisters to demonstrate new equipment.**



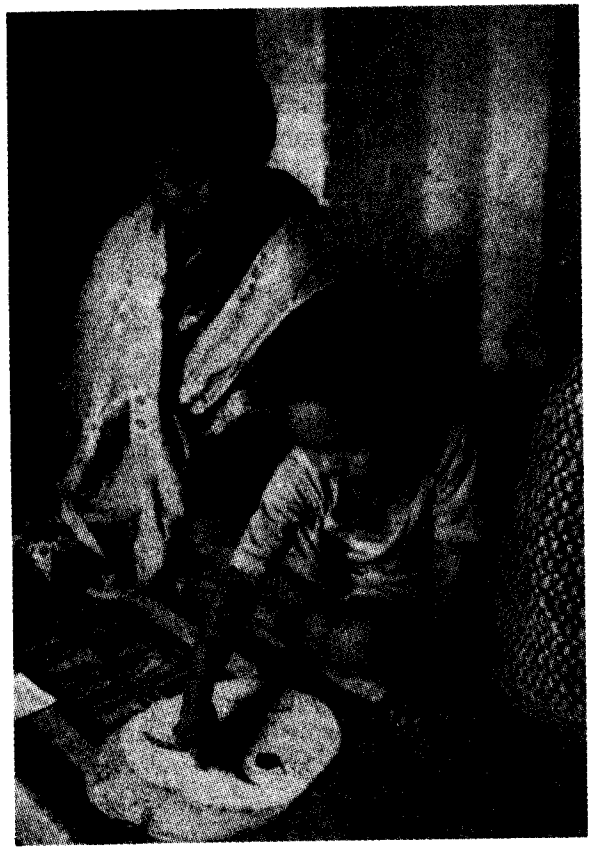
Explanation

Some children may refuse to try, or will be afraid of new playthings, aids, or special seating. If another child tries it first, and shows he likes it, the child will often want to try it also.

REMEMBER: Good teaching will make a difference. *How well* you teach, play, and express affection is more important than *how much* time you spend at it.



A teacher from Jan Madhyam (Delhi) helping a child to experiment with playground equipment.



A mentally retarded child learns the parts of a face by placing cut-out cardboard parts on a paper face. (Samadhan, New Delhi, India)



Puppets are also used to teach mentally retarded children in Samadhan. Each puppet wears clothes of one color and has the name of that color. The children learn the puppets' names–and so begin to learn the colors.

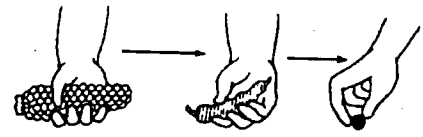
CHAPTER 36

Early Stimulation and Development Activities

On the next pages are activities to help young children's development. They are especially valuable for children who are mentally and physically delayed. They are also useful for children who are mentally normal but whose physical ***disabilities*** make both ***physical*** and ***mental*** development slow or difficult.

In this chapter we describe activities for early skills in the order in which they usually develop. So we start with head control, then progress to more advanced levels: reaching, grasping, sitting and balance, scooting, crawling, standing and walking, and language. (Self-care activities including eating, dressing, and toilet training are discussed in later chapters.)

In any area of development, such as head control or use of the hands, a child also advances through different stages of ability. For example, in developing grip, first a child can grasp only with the whole hand, later with thumb and finger.



To decide which activities to begin with, start by using the charts on pages 360 and 361 to **determine the developmental level** of your child. Then look through pages 372 to 386 and **pick those activities that are next in line for your child.** After she learns these activities, go on to the next.

A child advances in many areas of development at once. Try to help her in several areas at the same time. **In each area, pick activities that help her do better what she already does, and then to take the next step.**

Often an activity that helps a child to develop in one area also helps in others.



For example, we put the activity with this picture under **"head control."** But the activity also helps to develop use of **the senses** (eyes, touch, sound), **hand control, eye–hand coordination, balance while sitting,** and **flexibility of the body** (twisting to one side). If done in a friendly way, with praise, it can **develop confidence** and **ability to relate** to other people. And if father talks to the child as they play, naming each object and action, it also prepares the child for learning language.

When helping your child with these learning activities, remember to **introduce new skills in small steps** that the child can easily learn. **Praise her each time she succeeds, or tries hard or even makes an attempt at doing the activity.** Follow the suggestions on pages 364 to 368 for helping the child develop these new skills.

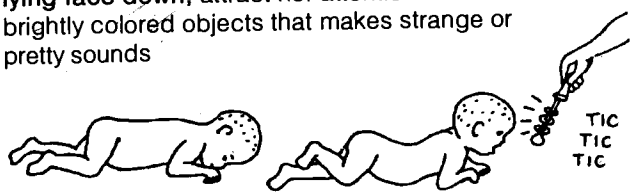
CAUTION: Many activities in this chapter are useful for children with cerebral palsy or other physical disabilities. However, some must be changed or adapted. Read the chapters that apply to your child's disability. ***Above all:*** USE YOUR HEAD. OBSERVE HOW YOUR CHILD RESPONDS. NOTICE HOW AN ACTIVITY HELPS–OR HINDERS–THE CHILD'S WHOLE DEVELOPMENT. **DO NOT SIMPLY FOLLOW THE INSTRUCTIONS. ADAPT OR INVENT ACTIVITIES TO MEET YOUR CHILD'S NEEDS.**

CP

1. Activities to help the child lift and control her head (and use her eyes and ears)

CP One of the first skills a normal baby develops is the ability to lift the head and control its movement. Head control is needed before a child can learn to roll, sit, or crawl. Normally, a newborn child can lift or hold her head up for a moment, and she develops fairly good head control in the first months of life. **Children with developmental delay are often slow to develop head control. We need to help them to develop reasonable head control before trying to help them to roll, sit,crawl, or walk.**

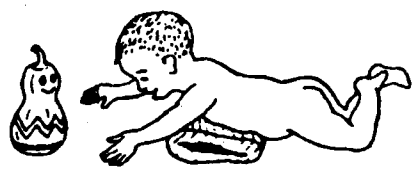
To encourage the child to raise her head **when lying face down,** attract her attention with brightly colored objects that makes strange or pretty sounds



If she does, not lift her head, to help her, put her like this. Press firmly on the *muscles* on each side of the back-bone and slowly bring your hand from her neck toward her hips.



If the baby has trouble raising her head because of a weak back or shoulders, try placing a blanket, rolled bed sheet or a pillow under her chest and shoulders. Get down in front of her talk to her. Or put a toy within reach to stimulate interest and movement.

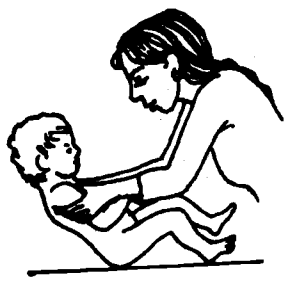


Some children can do more if they lie on a 'wedge' (see p.695)

If the child has trouble lifting her head when lying face down, lay her against your body so that she is almost upright. This way she needs less strength to lift her head.

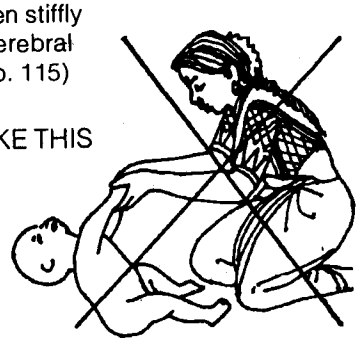


CP To help her develop head control when **lying face up,** take her upper arms and pull her up gently until her head hangs back a little, then lay her down again.

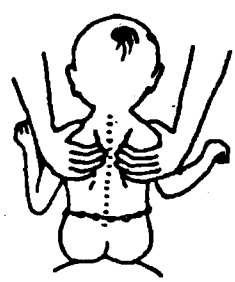


CAUTION: **Do not pull the child up like this if her head hangs back.** As you begin to lift her, watch to see if her neck muscles tighten. If not, do not pull her up. Also, do not pull the child up like this if it causes her legs to straighten stiffly (see "Cerebral Palsy," p. 115)

NOT LIKE THIS



If a child with cerebral palsy stiffens as you pull his arms, try pulling the shoulder blades forward as you lift him up.



If the child cannot lift his head as you pull him up, then do not pull him up. Instead, sit the child up and gently tilt him back a little, encouraging him to hold his head up. Repeat often, and as he gains strength and control, gradually tilt him farther back – but do not let his head fall backward.



If the baby makes almost no effort to lift or hold her head when you feed her, instead of putting the nipple or food into her mouth, barely touch her lips with it, and make her come forward to get it.



GOOD CARRYING POSITIONS

Carrying the child like this helps develop good head control, when he is face down.



Positions that keep the hips and knees bent and the knees separate help relax and give better control to the child with cerebral palsy whose body straightens stiffly and whose knees press together.





Carrying baby like this frees his head and arms to move and look around.



As your child develops better head control, play with him, supporting his body firmly, but with his head and arms free. Attract his attention with interesting objects and sounds, so that he turns his head first to one side and then to the other.



2. Activities to encourage rolling and twisting

After a baby has fairly good head control, usually the next step in development is to roll over. Rolling involves sideways twisting of the head and body. Twisting, or **rotation of the upper body on the lower body, must be learned before a child can learn to crawl and later to walk.**

Babies normally learn by themselves to roll over. But children who are developmentally delayed will learn faster with special help and encouragement. Help the child learn first to lift and turn her head to the side, then her shoulders and body.

Attract the child's attention by holding a rattle or toy in front of her,



then move the toy to one side, so the child turns her head and shoulders to follow it.

Encourage her to reach sideways for the toy,



then move the toy upward, so that she twists onto her side and back.

If she does not roll over after various tries, help her by lifting her leg.

Also, help the child learn to roll from her back onto her side. Again, have her reach for a toy held to one side.

CP



Note: If the child has ***spasticity,*** you may need to help position this arm before she can roll over.



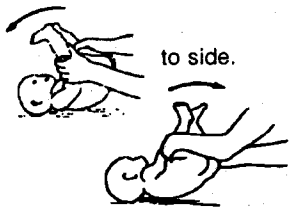
Note: If the child is very stiff, before doing other exercises or activities,

first help to relax him by swinging his legs back and forth.



CP

or curl up the child in a 'ball' and slowly roll his hips and legs from side to side.





Or twist his body to one side and then the other. Have him help by reaching for something he likes. Praise him when he does it.

Remember: THE FIRST RULE OF ***THERAPY:*** HELP ONLY AS MUCH AS NEEDED, ENCOURAGING THE CHILD TO DO MORE AND MORE FOR HERSELF.

3. Activities to help develop gripping, reaching, and hand-eye coordination

Most babies are born with a 'grasping reflex'. If you put your finger in their hand, the hand automatically grips it— so tightly you can lift up the child.

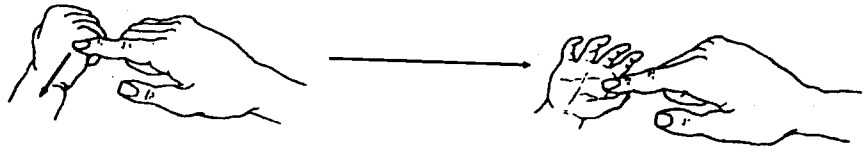


Usually this reflex goes away, and gradually the baby learns to hold things and let go as she chooses.

Babies who are slow to develop sometimes have little or no 'grasping reflex' and are slow to learn to hold things. For such children, these activities may help.

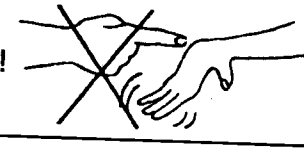
If she keeps her hand closed, stroke the outer edge of the hand from little finger to wrist.

This often causes the baby to lift and open her hand, and to grip your finger.



CAUTION: In a child with ***spasticity***, stroking the back of the hand may cause her to grip or open the hand stiffly without control. If so, do not do it, but look for ways that give her more control.

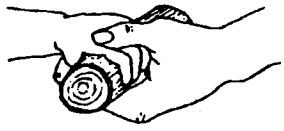
NO!



CP

When the child opens her hands well, but has trouble holding on,

place an object in her hand, and bend her fingers around it. Be sure the thumb is opposite the fingers.

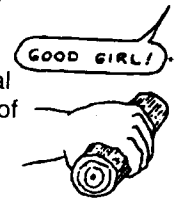


Gradually let go of her hand and pull the object up against her fingers or twist it from side to side.

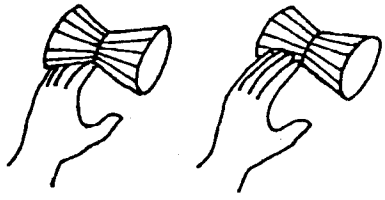


When you think she has a firm grip, let go

Repeat several times in each of the child's hands.

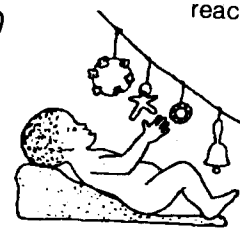


After the child can hold an object placed in her hand, encourage her to reach and grasp an object that just touches her fingertips.
First touch the top of her hand— then place it below her fingertips.



Encourage the baby to grasp by offering her rattles, bells, colorful toys, or something to eat on a stick.

Hang interesting toys, bells and rattles where the child can see and reach for them.



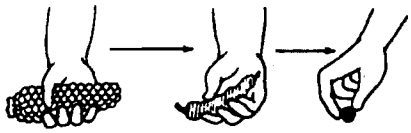
This way the child learns to move her hand forward to take hold of a toy.

If the child shows on awareness of her hand, hang little bell from her wrist.



Also, see page 399 for ways to help a child discover her hands by putting a sweet food on her finger and helping her take it to her mouth.

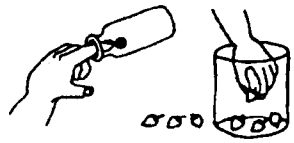
At first a child can only grasp large objects with her whole hand. As she grows she will be able to pick up and hold smaller things with thumb and fingers. Help her do this by playing with objects of different sizes.



To help strengthen grip, play 'tug-of-war' with the child–making it a fun game.



As the child gains more and more control, introduce toys and games that help develop **hand-eye coordination.** For ideas, see p. 389



Make games of putting things in and out of boxes and jars.

Playing with toys and imitating the work and play of others help the child gain more skillful use of his hands.

4. Activities for body control,balance, and sitting

CP

After a child gains good head control, he normally starts sitting through these stages.

sits when placed in a sitting position and held



sits, keeping balance with arms



balances with body while sitting, freeing hands for play

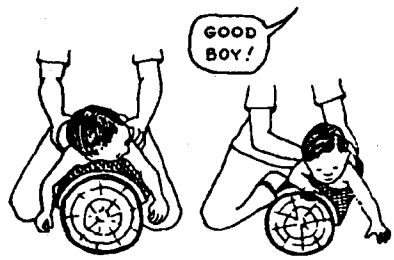


sits up alone from a lying position



In order to sit well a child needs to be able to hold her body up, to use her hands to catch and support herself , and finally to balance with her body so that she can turn and reach.

If the child simply falls over when you sit him up, help him develop with his arms. Put him on a log, hold his hips, and slowly roll him sideways. Encourage him to 'catch' himself with a hand.



Or do the same thing with the child on your belly.



After the child learns to 'catch' herself when lying, sit her up, hold her above the hips, and gently push her from side to side.



and forward and backward so that she learns to catch and support herself with her arms.



CAUTION: The child must be able to raise and turn her head before she can raise her body.

To help your child gain balance sitting, first sit her on your knees facing you.



Hold her loosely so her body can adapt to leaning.

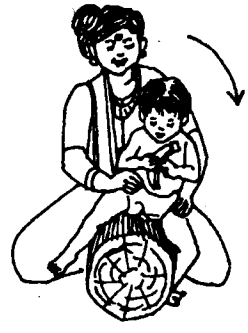
Later, you can sit her facing out so that she can see what is going on around her.



Slowly lift one knee to lean her gently to one side. Then the other, so that she learns to bend her body to stay seated.

You can do the same thing with the child sitting on a log.

As he gets better balance, move your hands down to his hips and then thighs, so that he depends less on your support.

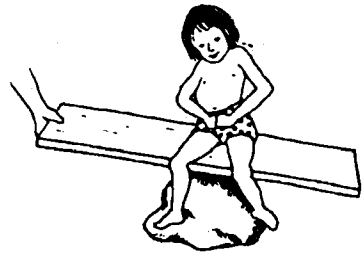


Give him something to hold so that he learns to use his body and not his arms to keep his balance.

With an older child who has difficulty with balance, you can do the same thing on a 'tilt board'.



At first let her catch herself with her arms.



Later, see how long she can do it holding her hands together. Make it a game.

Or you can do the same on a large ball.



Tilt it to **one side and the other** and also **forward and back.**



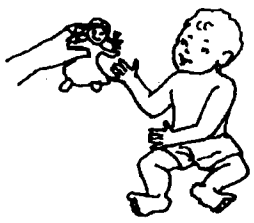
Note: You can also do these exercise by sitting the child on a table and gently pushing him backward, sideways, and forward. But **it is better to tip what he is sitting on.**

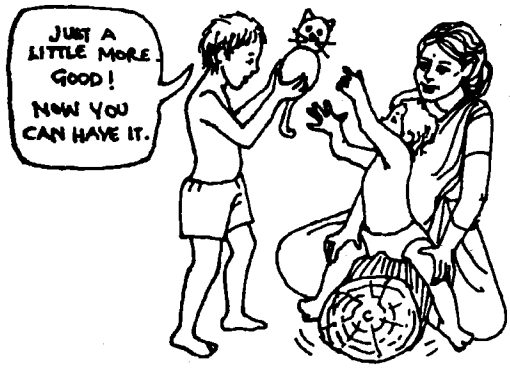
Pushing him causes him to 'catch himself' from falling with his arms.

Tilting him causes him to use his body to keep his balance,which is a more advanced skill.

Help the child learn to keep her balance while using her hands and twisting her body.

sitting on the ground,





and sitting on a log or seat.

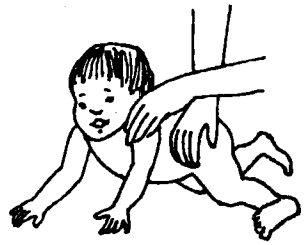
When the child can sit by herself, help her learn to sit up,

from lying on her back,



As the child starts to rise, push on the higher hip.

and from lying on her belly.



First help her lift her shoulders.

Press down and back on hip.



Help her roll to one side, rise onto one elbow, and sit.

Help her to sit up herself. **Do not pull her up. Praise her each time she does well, or tries hard.** Help her less and less until she can sit up alone.

Some children will need seating aids to sit well. To help improve balance, the aid should be **as low as possible** and let the child sit straight. Often, firmly supporting the hips is enough. Here are 2 examples:





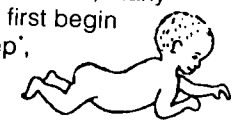
For the child who needs higher back support, simple 'corner seats' can be made of cardboard, wood, or poles in the ground.



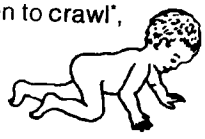
For more ideas on special seating and ***positioning***, see Chapters 66 and 67. For sitting aids, see p. 697.

5. Activities for creeping and crawling

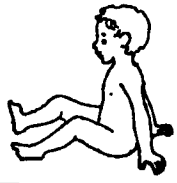
To move about, many babies first begin to **creep***,



and then to **crawl***,



or to **scoot** on their bottom.



Note: Some babies **never crawl** but go directly form sitting to standing and walking. Whether or not they crawl often depends on cultural patterns and whether the family encourages it.

If the child can lift her head well when lying on her stomach, encourage her to begin creeping in these ways.

Put a toy or food the child likes just out of reach.

At first it may help to support his feet.



CAUTION: If the child has cerebral palsy, supporting the feet may cause legs to straighten stiffly. If this happens do not support her feet.

If the child cannot bring her leg forward to creep, help her by lifting the hip.

CP



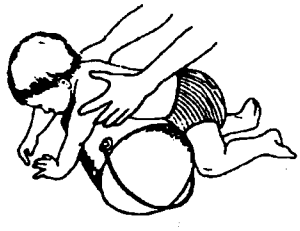
If the child has difficulty beginning to creep or crawl:

Let her 'ride' your knee. Play 'horsey'. Slowly move your knee up and down and sideways so that she shifts her weight from side to side.

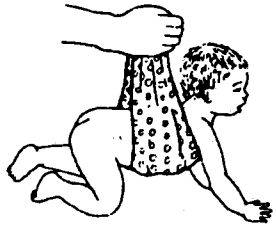


Encourage her to lift one hand off the ground and shift her weight to the other. Then help her to move forward.

Or put the child over a bucket or log, to help him bear weight with his elbows straight. Firmly push down on his shoulders and release. Repeat several times.



If the baby has trouble beginning to crawl, hold him up with a towel like this. As he gains strength, gradually support him less.



Move him from side to side so he shifts weight from one arm and leg to the other.



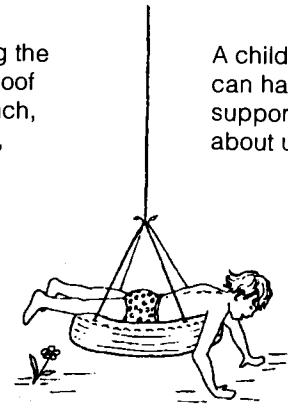
Older brothers and sisters can help.

Encourage the child to first reach–and later crawl–for something he wants.

*North American therapists use these terms in the reverse

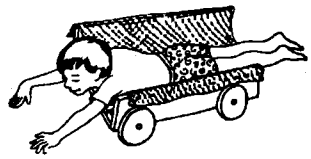


You can hang the child from a roof beam or branch, or a doorway, like this.

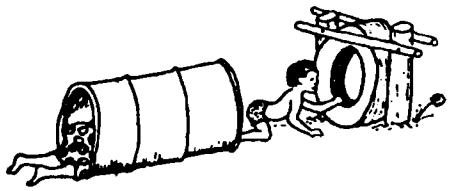


A child with spastic legs can hang with her legs supported to allow moving about using her arms.

Or makes a simple 'creeper'.



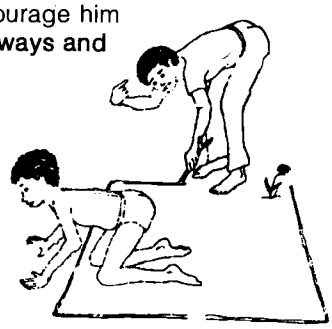
When the child has learned to crawl fairly well, have him play crawling games.



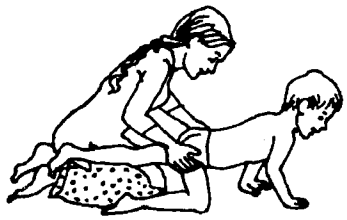
She can crawl up and down a small hill of sand or pile of straw. This will help improve her strength and balance.



To help an older child with balance problems to prepare for walking, encourage him to **crawl sideways and backward.**

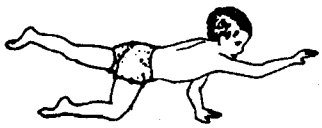


Also, have him hold one leg or arm off the ground and shift his weight back and forth.



At first, you may need to hold up one limb while you slowly rock him from side to side.

Later, have him practice holding one arm and the opposite leg off the ground at the same time.

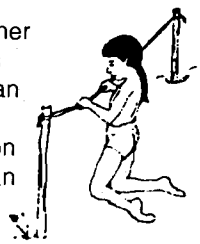




A 'rock board' is fun and helps balance.



After a child gets her balance on hands and knees, you can help her begin to stand–and walk–on her knees. She can walk sideways along the rope.



CAUTION: Do not do this in a child with spasticity whose knees bend a lot when she stands.

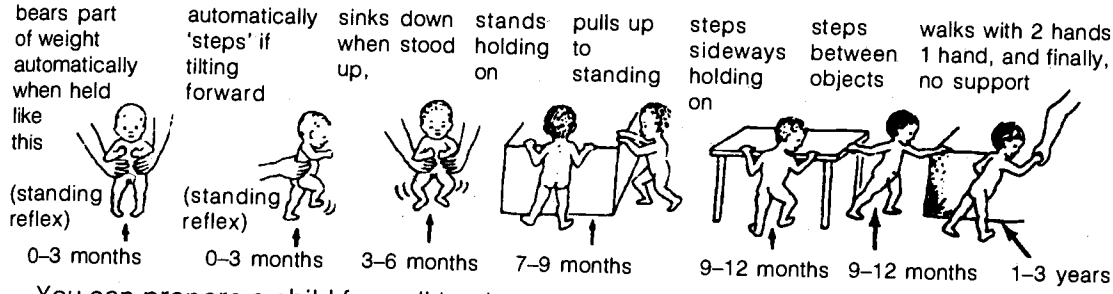
There are many ways the child can practice standing on her knees and shifting her weight—ways that are fun and include her in family activities.



CP

6. Activities for standing, walking, and balance

Normally a child progresses through these stages:



You can prepare a child for walking by encouraging each of the above stages as the child develops.

> ***CAUTION:*** If the child cannot balance when sitting, do not work on walking yet. Help her develop sitting balance first.

Hold the baby so that she uses the **early stepping reflex** to strengthen her legs. You can even bounce the baby gently.



When the child begins to stand, support her hips with your hands. Spread her feet apart to form a wide base. First do this from in front, later from behind.

As she gains better balance, you can provide a light support at the shoulders.



CP

> ***CAUTION:*** In children with spasticity, this activity may increase muscle stiffness DO NOT DO IT. (See p. 103 and 359.)



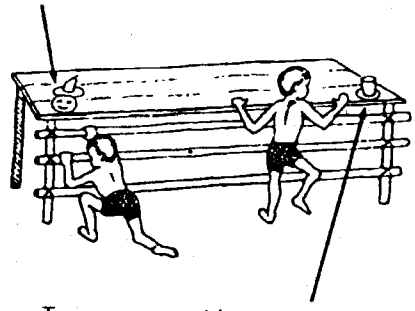
Move her gently from side to side, so that she learns to shift her weight from one leg to the other.

Or have the child hold a hose or rope. Because it is flexible, he needs to balance more.



Later, he can hold onto the rope with one hand only.

To encourage a child to pull up to standing, put a toy he likes on the edge of a table.



To encourage him to take steps, put something he likes at the other end of the table.

When a child can almost walk alone but is afraid of falling, tie a cloth around his chest.

Hold the cloth, but let it hang **completely** loose. Be ready to catch him if he falls.



> ***CAUTION:*** Do not let the child hang by the cloth. Have him bear his own weight. The cloth is only to catch him if he falls.

Other activities for **improving balance:**

Hold the child **loosely** under the arms and gently tip him from side to side and forward and backward. Allow him to return to a straight position. Turn it into a game.



At first support the child while you do this. When his balance improves, do it without supporting him–but be ready to catch him if he falls.

Practice walking sideways and backward.

Note: Walking backward helps children who tend to walk tiptoe to bring their heels down.



It is better to hold a child:

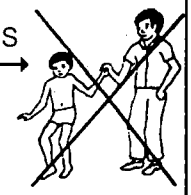


LIKE THIS ←

His balance is centered in his body.

NOT LIKE THIS →

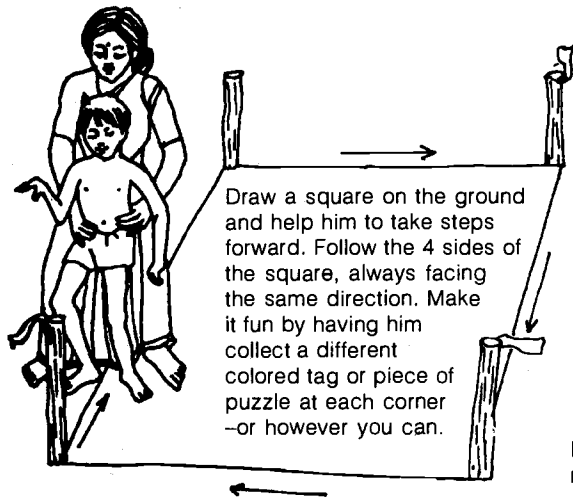
His balance is off center



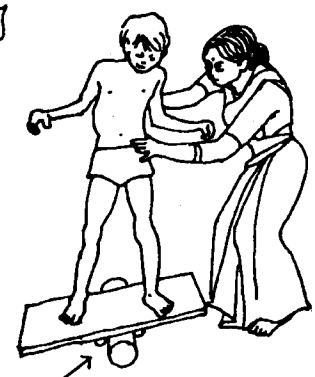
Support your child only as much as he needs, until he can walk by himself.

For the **older child** with poor balance, a homemade **balance board** will turn developing better balance into a game. Move slowly at first– especially with a child with cerebral palsy.

CP



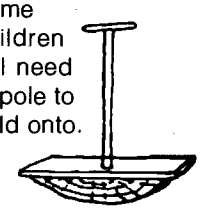
Draw a square on the ground and help him to take steps forward. Follow the 4 sides of the square, always facing the same direction. Make it fun by having him collect a different colored tag or piece of puzzle at each corner –or however you can.



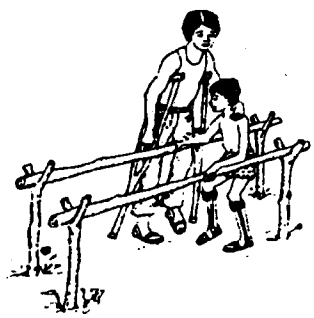
Blocks to prevent rolling sideways.

A balance board with a wide rocker is better because it rocks more smoothly. (see p. 700).

Some children will need a pole to hold onto.



Simple homemade **parallel bars** can help a child with weak legs or a balance problem get started walking.



Homemade **pushcarts** or **walkers** can provide both support and independence for the child who is learning to walk or who has balance problems.





A simple **wooden walker** with plywood wheels helps this developmentally delayed child begin to walk. (For designs of walkers, see p. 705.)

7. Activities for communication and speech

A normal child's ability to communicate develops through these stages:

expresses needs through body movements, looks on the face, and crying



0–1 months

makes 'happy sounds'–coos and gurgles



1–2 months

babbles–listens to sounds and tries to imitate



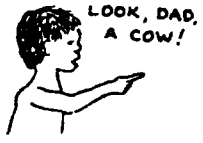
4–8 months

says a few words



8–12 months

begins to put words (and ideas) together

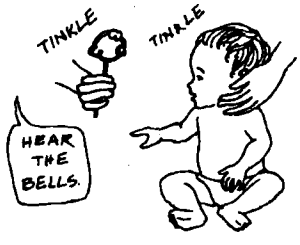


12 months–3 years

Learning that prepares a baby for speech begins early, long before she says her first word. Speech develops out of body movement, use of the mouth and tongue in eating, and use of the senses–through interaction with people and things.

One of the early stages in a baby's development of speech is noticing and responding to different sounds. A delayed child may need extra help and stimulation:

Make noises with bells, rattles, clickers, and drums, first directly in front of the baby, then to one side, so that she turns her head. Talk and sing to the child.



If she does not turn her head, bring the toy back so she can see it, and move it away again.

Or, gently turn her head so that she sees what makes the sound. Help her less and less–until she turns her head alone.

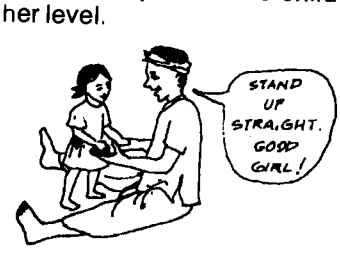
Repeat the babble of the child: have conversations with him in his language. But when he begins to say words, repeat and pronounce them clearly and correctly–**do not use 'baby talk'.**



To get the child used to language, **explain everything you do with him.** Use clear, simple words–the same ones each time. name toys, objects, body parts, food items and things related to him. Repeat often.



Understanding language depends not only on hearing, but also on watching lips and looks. So **speak to the child on her level.**



LIKE THIS NOT LIKE THIS

A child understands words before he can speak them. Play **question games** to help him listen and learn; he can answer your questions by pointing, nodding, or shaking his head.

Repeat words. Make small requests. Reward success.



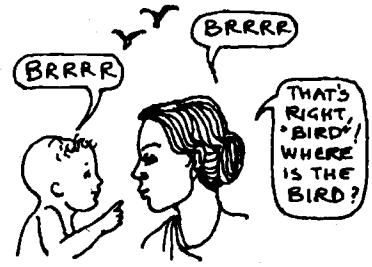
Rhythm is important to language development. Sing songs, play music, and have the child imitate body movements: clap your hands, touch your toes, or beat a drum.



Imitate the sounds that baby makes and have him copy the same sounds when you make them. Then say works similar to those sounds.

Also, imitate use of the mouth: open wide, close tight, stick out tongue, blow air, push lips in and out.

CAUTION: Encourage use of gestures, but not so much that the child does not feel the need to try to use words.



SPECIAL PROBLEMS IN SPEECH DEVELOPMENT

(CP)

A mouth that hangs open or drools is a passive (inactive) mouth. It makes development of language more difficult. Often children With Down syndrome or the floppy type of cerebral palsy have this problem.

Here are some suggestions to help correct the problem of drooling and to help strengthen the mouth, lips, and tongue for eating and speaking ability.

CAUTION: If the child's mouth hangs open and she drools, do not keep telling her to close it! This will not help and will only frustrate the child.



Stroke or tap the upper lip, or gently press the lower lip several times.



Or, gently stretch the lip muscles. This may help the child to close his mouth.



To strengthen the tongue and lips, put honey or a sweet, sticky food on the upper and lower lips. Have the child lick it off.





You can also put sticky food on the inside of the front teeth and roof of the mouth. Licking this food helps prepare the tongue for saying the letters T, D, N, G, H, J and L.

Also have the child lick sticky food from a spoon and lick or suck 'suckers' and other foods or candies.



Put food into the side of the mouth and behind the teeth so that the child exercises the tongue. Also, have the child try to take food off a spoon with his lips.

Begin to give the child solid foods, and foods she needs to chew, as early as she can take them (after 4 months). This helps develop the jaw and mouth.

CAUTIONS:
1. Do not do licking exercises in a child with cerebral palsy whose tongue pushes forward without control. This can make the 'tongue thrusting' worse.
2. After giving the child sweet or sticky food, take extra care to clean teeth well.

Play games in which you have the child:

suck and blow bubbles through a straw



blow soap bubbles



blow air



blow whistles

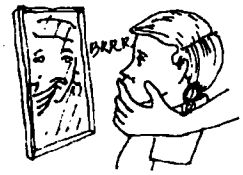


> ***CAUTION:*** For children with cerebral palsy, these blowing exercises may increase the uncontrolled tightening of muscles or twisting of the mouth. If so, DO NOT USE THEM.

CP

Encourage mouthing and chewing on clean toys (but not thumb sucking).

Help the child discover how to make different sounds by flapping her lips up and down with your finger,

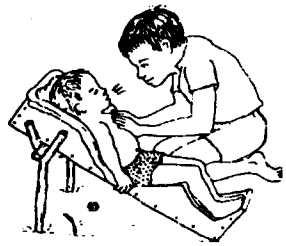


or by squeezing them together as she makes sounds.



For a child with cerebral palsy, you can help him control his mouth for eating or speaking by stabilizing his body in a firm position. Choose the position in which he is most relaxed (least spastic). This usually means bending the head, shoulders, and hips forward. For this reason it is sometimes said:

"WE CAN CONTROL THE LIPS THROUGH THE HIPS."



You can help the child make different sounds by pushing on and jiggling his chest.

Imitate the sounds he makes and encourage him to make them by himself.

If the child has trouble with controlling his jaw when he tries to speak, try using 'jaw control' with your fingers, like this. (See p. 395.)

Have him repeat sounds that require jaw movement.



When the child has difficulty pronouncing words, do not correct her. Instead, repeat the words correctly and clearly, showing that you understand.



REMEMBER– The child needs a lot of stimulation of all her senses to develop language. Play with her, speak to her, and sing to her often. Ask her questions and give her time to answer. **Do not try to 'make her learn', but give her many learning opportunities.** Ask questions that need words for answers, not just 'yes' or 'no'.

Is your child deaf? If your child is slow to speak, check his hearing (see p. 541). Even if he hears some noises, he may not hear well enough to understand speech.

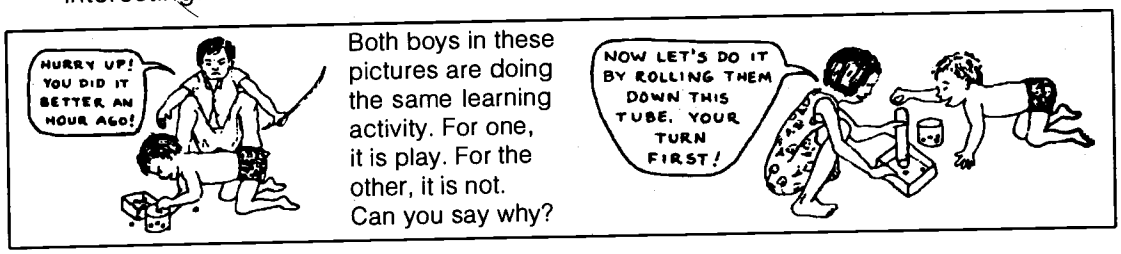
Also, some children who hear well may never be able to speak. For example, certain children with cerebral palsy cannot control their mouth, tongue, or voice muscles. For these children, as for young deaf children, we must look for other ways to communicate. (See Chapter 31.)

8. Early play activities and toys

Play is the way children learn best. **So try to turn every activity you do with a child into some kind of play or game.**

It is not what you do, but **how you do it** that makes something play. As long as it is fun and the child wants to do it, if is play. But if it stops being fun, or the child does it only because 'he has to', it stops being play. Small children (and big children who learn slowly) only stay interested in the same thing for a short time. The child soon gets bored and stops learning. Therefore, for activities to be play and stay play,

1. continue with the same activity for a short time only, and
2. look for ways to keep changing the activity a little so that it is always new and interesting.



Both boys in these pictures are doing the same learning activity. For one, it is play. For the other, it is not. Can you say why?

Not all play has to be organized or planned; often the child learns most when it is not. Play needs some aspect of **adventure, surprise,** and **freedom.** It is important that a child learn to **play with other children.** But it is also important that she be given the chance and encouraged to **play alone.** She needs to learn to enjoy and live with other people–and with herself.

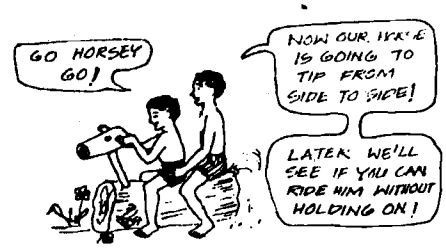
We do not talk much about play separately, because mostly it is not a separate activity. It is the best way to do almost any activity. For this reason, in this whole chapter–and book–we often give ideas for turning exercise, therapy, and learning into play.

Play activities, like other activities, should be picked so that they 'fit' a child's level of development and help him move one step farther. They should be HARD ENOUGH TO BE INTERESTING, but EASY ENOUGH TO BE DONE WELL. For example :

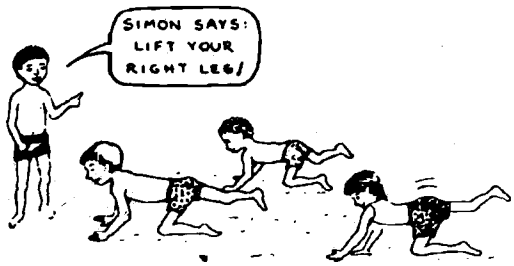
If the child is at the level of a very young baby, play games that help him use his eyes and hold up his head.



If the child is at the level where she sits, but finds it hard to keep her balance or open her knees, look for play that helps her with these.



If in preparation for standing and walking the child needs practice shifting weight from one knee to the other, you might try imitation games. Here are 2 ideas:



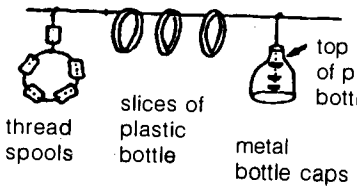


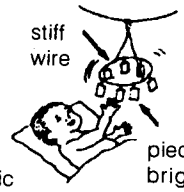
TOYS AND PLAYTHINGS TO STIMULATE A CHILD'S SENSES

Play is more important than toys. Almost anything–pots, flowers, sandals, fruit, keys, old horseshoe–can be used as a toy, if it is used in play.

Toys–or 'playthings'–offer stimulation for a child, both when she plays by herself and when she play with others. Many simple things in the home can be used as toys, or can be turned into them. **Here are some examples: mobiles made of cloth, dolls and birds, bamboo pieces, coloured papeir mache balls, rattles made of clay, wood or palm leaves, small tin containers with stones, seeds or shells.**

Hanging toys for baby to admire, touch, and handle can be made of many things.





Caring for babies provides a learning experience that combines work and play for the child who is gentle.



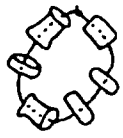
CAUTION: **Take care that toys are clean and safe for the child.**

Here are a few examples of interesting toys. Use your imagination and the resources of your family to make toys.

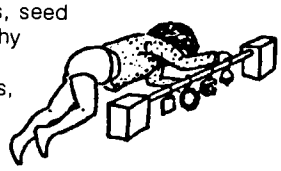
Toys for touching

soft clothes or blanket, baby animals, corn on the cob, finger paints, inner tubes for swimming, bathing nuts and bolts, toes and fingers, seed pods, mushy food, cloth doll, gourds, sand

clay, string chain, pulley gears, rocks beads, fruits mud

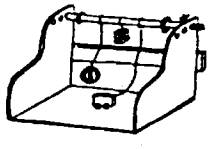


flowers dough



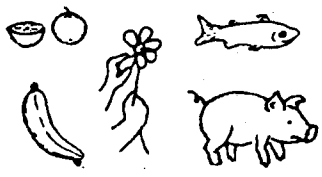


For children who have trouble controlling their movements, and often drop or lose their toys, it may help to tie the toys with string, as shown here.



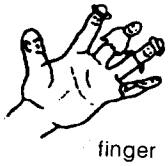
Toys to taste or smell

foods
flowers
fruits
animals
spices
perfumes



Toys for seeing

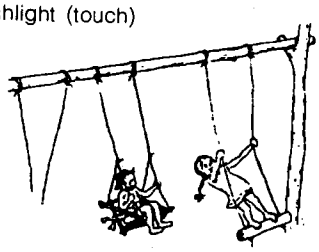
mirrors colors
colored paper or tinfoil
daily family activity,
puppets, old magazines
with pictures, crystal
glass, pictures,
crystal glass pieces
(rainbow maker) flashlight (touch)



finger puppets

Toys for balance

swings
hammocks
seesaws
rocking horses



Toys for hearing

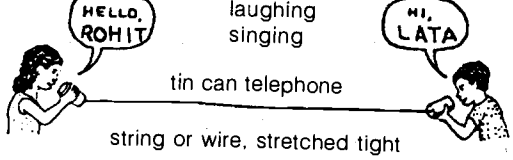
rattles, guitar
flutes, drum
bells
bracelets on
baby's wrist
and ankles
that tinkle
when baby
moves



marimba or xylophone, wind, chimes whistles, pet, birds, animal sounds, seashells or other echo, toys talking laughing singing



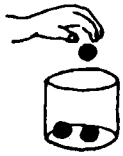
a pan as a drum



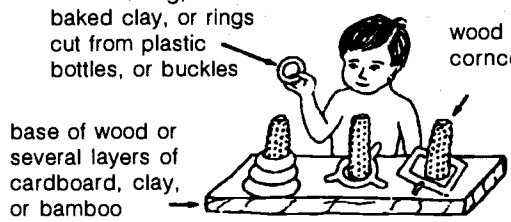
TOYS TO DEVELOP A CHILD'S MIND AND HAND–EYE COORDINATION

Learning to fit things into things

Start simple–dropping objects into a jar, then taking them out again.

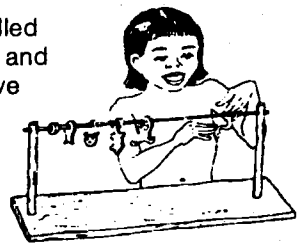


As the child develops, make things more complex.



Note: Rings can be of different sizes, colors or shapes so that the child can also learn to match these.

To help develop controlled movement of the hands and arms, the child can move beads or blocks along a rod or wire.



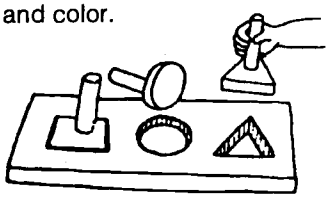
Using animals or funny figures makes the exercise more fun. Other children will be more likely to join in the game.



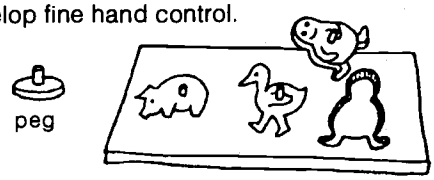
Threading beads, empty spools, or cut pieces of bamboo is another activity which improves controlled movement of hands and arms. Gradually reduce the size of objects to be threaded.

Matching games

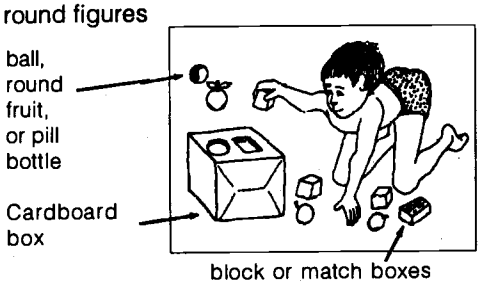
The child can match objects of similar shape, size, and color.



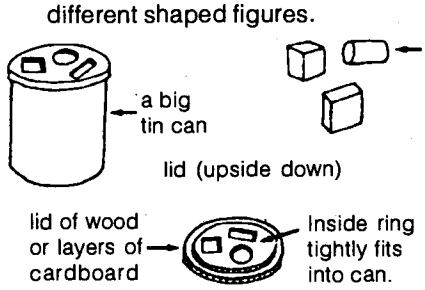
Small pegs glued onto cut–out pieces help develop fine hand control.



Start with simpler games with square or round figures



Then progress to more complicated games with different shaped figures.



You can teach colour, shape and size with things available at home and in the surroundings. For example: colours of flowers, shapes of leaves and vegetables etc.



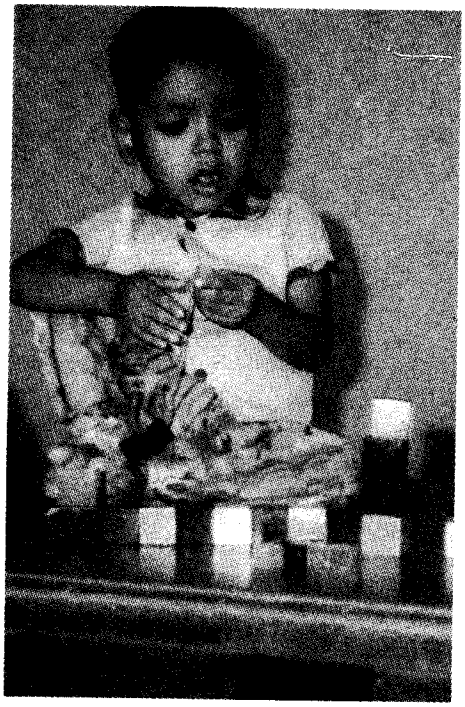
Puzzles

Jigsaw and block puzzles and building blocks also help a child learn how shapes and colors fit together. Suggestions for making different puzzles are on p. 569.

Many more ideas for simple toys are included in Chapter 50, "A Children's Workshop For Making Toys," p. 559 to 573.

A child with developmental delay learns fine motor skills, visual motor skills, counting and sequencing, color identification and differentiation with the help of the MUPET. It is used for assessment of functional intelligence and language stimulation.

MUPET – (Multi Purpose Educational Tool) is made of wood, in primary colors and consists of a set of 16 one inch and 24 half inch cubes with holes and a string. It is made at SAMADHAN's (New Delhi) vocational training centre by mentally retarded children and is used effectively in its early intervention program.



NOTES

CHAPTER 37

Feeding

Feeding is one of the first abilities that a child develops to meet her needs. Even a newborn baby has reflexes that cause her to:

CP

turn her head to seek the breast when her cheek



suck and swallow



and cry when hungry



By a few months of age, the child learns to take solid food in her mouth and eat it.



Normally a child's feeding skills gradually increase without any special training. She learns first to use her lips and tongue to suck and swallow liquids. Later she learns to bite and chew solid foods, and to take food to her mouth with her hands. The early head–turning and sucking reflexes gradually go away as she learns to control her feeding movements.

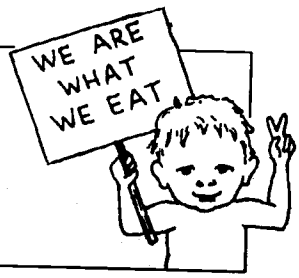
Some children, however, do not develop feeding skills easily or naturally. This may be because the child's whole **development is slow (*retarded*)**. Or, because the child has a particular **physical difficulty** (such as a hole in the roof of her mouth–see "Cleft Palate", p.140).

Children with **cerebral palsy** often have feeding difficulties, which are sometimes severe. Difficulty with sucking (or being unable to suck) may be the first sign in a child who later develops other signs of cerebral palsy. Or the child may have trouble swallowing, and easily choke on food. Uncontrolled movements of the body, pushing out the tongue, or floppy, inactive lips may also be a problem.

CP

One reason that some disabled children are slow to develop self–feeding skills is that their families continue to do everything for them. Because of a child's other difficulties, her family may continue to treat her as a baby. They may give her only liquids, and put everything into her mouth, rather than encouraging her to do more for herself. Sometimes, parents feel that a liquid diet is better for avoiding constipation, a common problem with children who have cerebral palsy. Thus a large number of children do not get the nutrition that is necessary for their age.

REMEMBER: Helping the child develop feeding skills as early as possible is of special importance because **good nutrition is essential for health and life. The food needs of a disabled child are the same as for any child.**
Good use of the lips and tongue when feeding is also important for future speech.



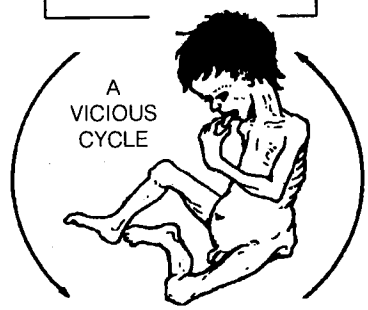
POOR NUTRITION IN DISABLED CHILDREN

Poor nutrition or 'malnutrition' usually results from not getting enough to eat and is one of the most common causes of health problems. With its signs of weakness, thinness, failure to grow, and reduced ability to fight off illness, poor nutrition might be considered a *'disability'* itself. It affects at least 1 out of every 6 of the world's children, mainly those who live in poor countries.

In this book, we do not discuss the problems of malnutrition in detail, because they are covered in most primary care handbooks (see ***Where There Is No Doctor***, Chapter 11). However, a special warning is called for.

WARNING: **Disabled children are often in greater danger of malnutrition than are other children.**

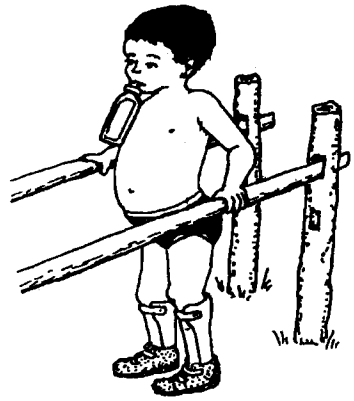
The child who is physically and mentally slow is more likely to be neglected and not fed enough.



Not eating enough slows down both physical and mental development.

Sometimes this is because the child has difficulty sucking, swallowing, or holding food. Sometimes it is because the family gives more food to the children who are stronger and more able to help with daily work. Sometimes, however, it is because parents, although they treat their disabled child with extra love and care, keep bottle feeding him (with milk, rice water, or sugared drinks) until he is 3 or 4 years old or older. They keep treating–and feeding–their child like a baby, even though he is growing bigger and needs the same variety and quantity of foods that other children need.

To give a child only–or mainly–milk and sweet drinks after 6 months of age may keep the child fat. But he will slowly become malnourished. Milk and sweet drinks lack iron, so that the child may become more and more pale, or anemic (weak blood).



This 4-year-old with spina bifida has no difficulty eating any foods. Yet his family still treats him like a baby– complete with a baby bottle filled with a sweet drink– just because he is 'disabled'.



Normal: Lips, tongue and finger-nails have a reddish, healthy color.

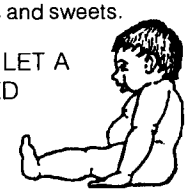


Anemic: Lips, tongue and finger-nails, pale. Lack of energy. Tires quickly.

REMEMBER: **A disabled child needs the same foods that other children of the same age need.**

CAUTION: It is important that disabled children get enough to eat. It is also **important that they do not eat too much and get fat.** Extra weight makes it more difficult for a weak child to move about. If the child is getting fat, give him less fatty foods and sweets.

DO NOT LET A DISABLED CHILD GET FAT!



THE BEST FOOD FOR YOUR YOUNG CHILD

THE FIRST 4 TO 6 MONTHS

Give **breast milk** and **nothing else**



BREAST IS BEST because breast milk contains the **ideal combination of foods** that the child needs, is **clean,** and is always the right temperature. Also, **breast milk contains 'antibodies'** from the mother that protects the baby against infections.



Therefore, breast milk is especially important for children more likely to get *infections,* such as a child with Down syndrome (see p.338) or a child who often chokes on her food and might get pneumonia.

Breast milk is healthier for babies than other milks or milk made from milk powder.

If the baby cannot suck, a mother can milk her breasts :



And then give the baby her milk with a cup and spoon.



WARNING: Avoid baby bottles whenever possible. They often spread infections.

NO





Cup and spoon feeding is safer.

FROM 4 TO 6 MONTHS AND AFTER



Continue breast feeding and also begin to give the baby other foods–juices rich in vitamins, mash of green leafy seasonal fruits and vegetables, lentils boiled, skinned, and mashed), porridge made from suji and dalia, egg yolks, and other local staples such as rice, ragi, jawar, bajra and wheat.



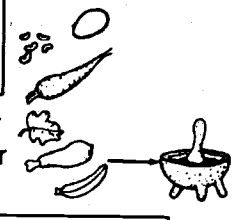
Small stomachs need food often. Feed children under 1 year old at least **5 times a day**– and give them snacks between meals.

If the child has trouble eating solid foods, do not keep giving only milk or formula or 'rice water'. Even mother's milk alone is not enough after 6 months.

CAUTION: Many children develop diarrhoea or vomit when they start on solid foods. But this is normally only an initial reaction and parents should not discontinue solid foods and revert to liquids. This will cause malnutrition. It might be better to try one type of food at a time.



Mash or grind up other foods to form a drink or mush.



By 8 months to 1 year of age the child should be eating the same food as the rest of the family–even if it has to be mashed or turned into liquids.



Successful feeding involves the whole child

The more difficult it is for a child to control his body movements, the more difficult it will be for him to feed himself. A child with Down syndrome may have trouble feeding because of weak mouth and lips and poor head control. But the feeding problems of a child with cerebral palsy are more complex. They may include: lack of mouth, head, and body control; poor sitting balance; difficulty holding things and taking them to his mouth. We must consider all these things when trying to help the child feed more effectively.

(CP)

It is not enough simply to put food or pour drink into the mouth of a child who has difficulty sucking, eating, and drinking. First, we must look for ways to help the child learn to suck, swallow, eat, and drink more normally and effectively. Here are some suggestions.

POSITIONS FOR FEEDING

Be sure the child is in a good position ***before*** you begin feeding her. The position will make feeding either easier and safer, or more difficult and unsafe.

Do not feed the baby while she is lying on her back because this increases the chance of choking.

In a child with cerebral palsy, it often causes backward stiffening, and makes sucking and swallowing more difficult.

WRONG



Feed the baby in a half sitting position with her head bent slightly forward.

In a child with cerebral palsy, to keep the head from pushing back, hold the shoulders forward, keep the hips bent, and push firmly on the chest.

RIGHT



Do not let the head tilt backward. It makes swallowing harder and may cause choking.

In a child with cerebral palsy, avoid pushing the head forward like this. It will cause the baby to push her head back more forcefully.

WRONG



Positions for feeding with a bottle, spoon, or finger are like those for breast feeding.

(CP)

If the baby does not suck and swallow well, the mother may think she should put a bigger hole in the nipple, tilt the baby's head back, and pour the milk into the baby's mouth.

But this may choke him, and it does not help him learn to suck well. It also increases chances of chest congestion.

WRONG

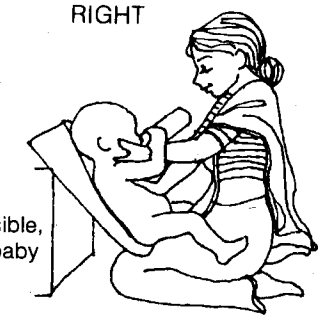


Position the baby so that the head is slightly forward, and the bottle comes from in front, not above.

Pushing gently on the chest helps stop backward stiffening so the baby can swallow better.

If possible, have baby hold bottle.

RIGHT



To avoid the backward stiffening, bend the shoulders and back forward, keeping the hips and knees bent. Be sure the head bends a little forward.

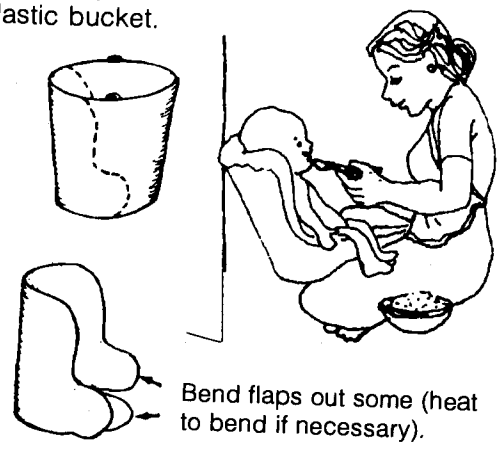
Place food below and in front of child, not above or behind him.

RIGHT



foot lift to keep the baby's knees higher.

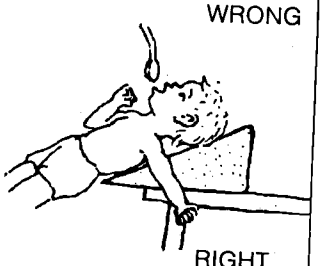
A simple **'baby seat'** can help the baby hold a good position while eating. Here is one idea using an old plastic bucket.



Bend flaps out some (heat to bend if necessary).

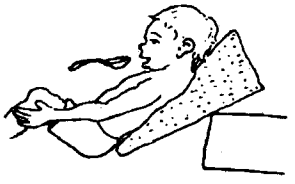
REMEMBER: When feeding a child with cerebral palsy, giving food **from above** often causes the head to press back and body to stiffen. It makes swallowing difficult. (CP)

WRONG



Giving food **from in front** helps stop stiffness and makes eating and swallowing easier.

RIGHT



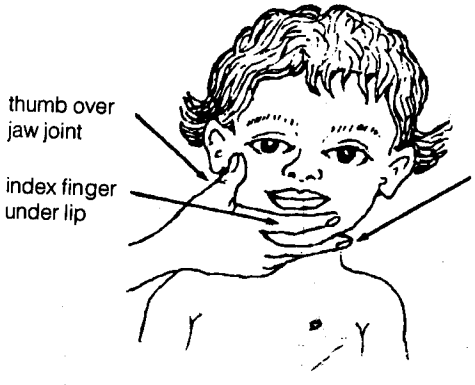
For other seating ideas, see p. 398.

HELPING CONTROL MOUTH FUNCTION

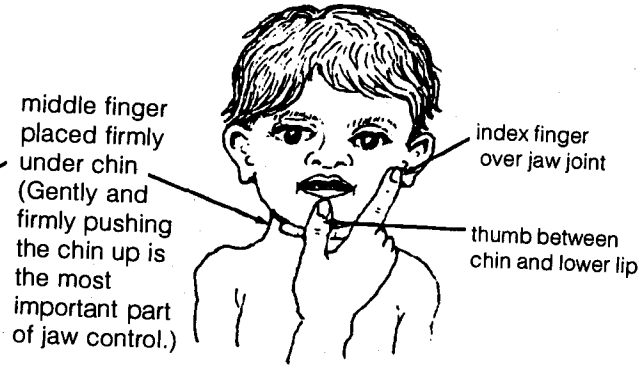
The child may also need help in improving the **sucking–swallowing reflex,** and her ability to eat from a **hand or spoon** and to **drink from a cup.** Sometimes these can be improved by using what is called 'jaw control'. (CP)

Jaw control. Before giving the breast, bottle, spoon or cup, place your hand over the child's jaw, like this:

if you sit beside the child



if the child is facing you



At first the child may push against your hand,but after she gets used to it, it should help her control the movement of her mouth and tongue. Be sure not to push her head back, but keep it bent forward slightly.

While you feed the child, **apply gentle, firm steady pressure**–not off and on.

Good positioning together with jaw control will help with several problems common in cerebral palsy, such as pushing the tongue forward, choking, and drooling (dribbling). **As mouth control improves, gradually lessen and finally stop jaw control.** (CP)

For more suggestions for controlling drooling and improving use of the lips and tongue, see the section on 'developing speech, p. 384.

(CP) For the child who has difficulty breast feeding (or bottle feeding), as you apply jaw control try bringing her cheeks forward with your fingers.

At the same time, push gently against the child's chest with your wrist. (This may help the child who tends to stiffen backward.)



If you bottle-feed the baby, an 'old-fashioned' large round nipple usually works best.

If the child still has trouble sucking, try making the hole in the nipple bigger and thickening the milk with corn meal, gelatin, or mashed food.



(CP) *CAUTION:* Jaw control helps in many children with developmental delay and cerebral palsy–but not all. After trying it for 2 or 3 weeks, if the child still resists it or shows increased problems, stop using jaw control.

Spoon Feeding

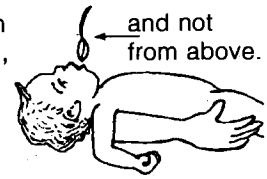
The child who has no sucking–swallowing reflex needs to be fed with a spoon.



Always give the spoon from in front,



not from the side,



and not from above.

RIGHT WRONG WRONG



YES

The best spoon is rounded and shallow.



NO

Not deep because this makes it hard for the lips to get out the food.



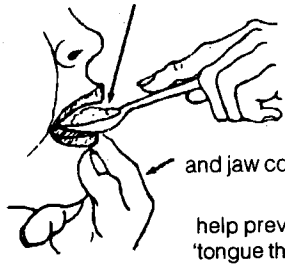
NO

And not long and pointed as this could cause choking.

'Tongue thrusting'

(CP) A baby sucks by moving her tongue forward and backward. For this reason, when the child begins to eat from a spoon, her tongue will at first push part of the food out of her mouth. She has to learn to use her tongue differently–pushing the food between the gums to chew, and to the back of her mouth to swallow. Children with developmental delay or cerebral palsy may have trouble learning to do this, and continue to push or 'thrust' the tongue forward for some time. **Do not mistake this for meaning she does not like the food.**

Applying firm pressure on tongue,



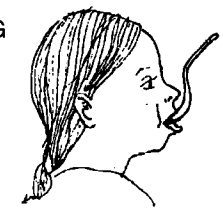
and jaw control, help prevent 'tongue thrust'.

Jaw control, although helpful, may not be enough to prevent this tongue thrusting. It also helps to **apply firm pressure with the back of the spoon on the tongue** as you feed the child. This helps keep the tongue from pushing forward and lets the child use his lips and tongue better.

CAUTION: Better to use a strong (metal) spoon and **NOT** a thin plastic one that might break when you push down the tongue.

Do **NOT** scrape the food onto the upper lip or teeth as you take the spoon out. Instead, let the child try to get the food off the spoon onto her tongue. To make it easier for her, start by putting only a little food on the end of the spoon. As you take the spoon out, make sure the mouth is closed so that the tongue can move the food inside and cannot push it out.

WRONG



If spoon feeding is too difficult, use your fingers. Here a mother holds her child in a good position on her lap, using her legs and body to give support.

With one hand she gives jaw control while she feeds him with the fingers of the other hand. Place a little food on the side or middle of the tongue–not on the front of it.



For spoon or finger feeding, it is best to start off with soft, mushy foods rather than liquids. Milk (even breast milk) or egg yolk can be mixed with rice paste, or porridge made of suji or dalia. You can also give small pieces of fruit, mashed greens and vegetables, and yogurt or soft cheese (paneer).

Hardest for the child to eat are combinations of liquids and solids–such as vegetable soup.

CAUTION: **Remember to wash your hands before feeding child with your fingers.**

Chewing

To help the child learn to chew, **put a bit of firm food in the side of her mouth between her teeth.** Use very small pieces of bread crust or chapati. Help her close her mouth using jaw control. (CP)

Biting off can be encouraged by pulling slightly on a long thin piece of food.

Or rub the piece of food against the teeth before putting it between them.

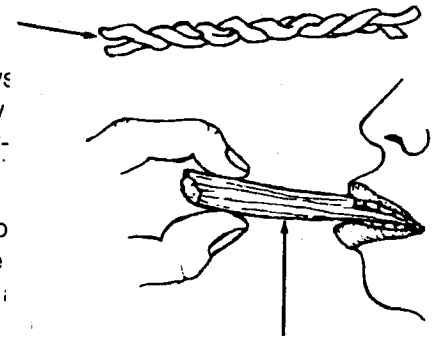


CAUTION: Do NOT open and close the child's jaw or help her chew. After she bites the food, **her jaw must stay closed or almost closed or almost closed.** To help her do this, apply steady firm pressure with jaw control. This should lead the child to make chewing motions. Let the jaw move some on its own. But **do NOT make chewing motions for the child!** This will only encourage abnormal movements.

If the child has difficulty chewing and chokes on pieces of food,try this:

Cut a piece of clean, soft cotton cord, or braid thin strip of cotton cloth. Soak or cook the cord in a tasty good food and hold the end while she bites and chews on it, squeezing out the nutritious juices. Help with jaw control. You can also cut out long thin pieces of sugar-cane and help the child bite and chew on it.

This method is completely safe. Because you hold o to the cord, the child cannot bite off pieces and choke on them . It is best to practice this at the beginning of meal while the child is still hungry.



A finger-shaped piece of tough cooked or dried meat or very tough chicken (old rooster) can be used instead of the cord. Be sure it is too tough for the child to chew pieces off of it,but juicy or tasty enough to give her pleasure.

CAUTION: if a piece of food slips back into the child's throat and gets stuck, bend the child far forward, and keep calm. The food should drop out. DO NOT pat the child on the back as this could cause the child to breathe in the food.
If the food does not fall out and the child cannot breathe, suddenly and forcefully squeeze the child's lower chest (see *Where There is No Doctor*, p. 115).

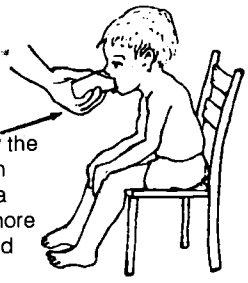
CP

Drinking

Succesfull drinking, like eating, involves the whole child. Body position is important. For example, in a child with cerebral palsy, to drink from a regular cup or glass, his head must be tilted back. But this can cause uncontrolled backward stiffening and possible choking.



However, if he uses a plastic cup with a piece cut out, he can drink without bending his head back.



This way the child can drink in a better, more controlled position.

The cup should have a projecting rim.



Cut out a space to fit around the child's nose.



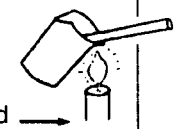
You can make a special cup from a plastic bottle.



Cut it like this.



Gently heat the rim and gradually bend it out with a round smooth rod or stick.





At first you may need to apply jaw control to help the child close her lips on the rim of the cup. Tilt the cup so that the liquid touches the upper lip and let the child do the rest. Do ***NOT*** take away the cup after each swallow as this may trigger pushing the head back or tongue out. It helps to start with thick liquids–like cooked cereals, rice mush, or yogurt.

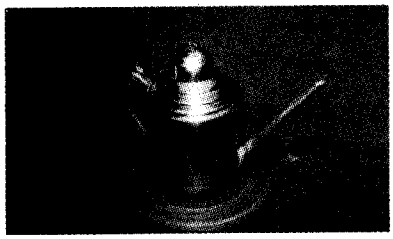


Photo : Avijit Kishore

Often you may find that things that are already being used in the community for other purposes, may be suitable as an aid for your child. This small kettle, commonly used in Dharavi (a slum in Bombay) was converted into a feeding cup by members of Karuna Sadan, Spastic Society of India, Bombay. The kettle is used for giving water and liquids to children in small quantities.

CP

Self–feeding

To be able to feed herself, a child needs more than control of her mouth, lips, and tongue. She also needs to be able to **sit with her head up,** to **pick things up,** and to take **them to her mouth.**



To prepare for self–feeding, encourage the child to play, taking his hands and toys to his mouth. Also, encourage him, when sitting, to balance while he uses both hands (see p.119 and 377).

A child with poor balance or uncontrolled movements will at first need special seating adapted to her needs.

A HIGH CHAIR

Try one or more straps, to see what works best.



A CARDBOARD BOX SEAT





Some children with cerebral palsy may only need a foot strap to stay in a good position (to keep the body from straightening stiffly as shown above).

CAUTION: Seats or straps that limit movement should be used only until the child learns to control her position without being tied or held. **Special seating should help the child to do more and to move more freely. It should not become a prison!** For more seating ideas, see p. 395, 697, and Chapter 66.

When a child is slow in using her hands to grasp things, or to take things to her mouth, you can help her discover how to use her hands and feed herself, like this:

Put the child's finger in a food she especially likes.



Then lift her finger to her mouth.



Help her to do more and more, step by step, until she does it alone.



Little by little help her less and less. Lift her hand to her mouth and touch her lips with the food. See if she will then put it into her mouth. When she has learned this, lift her hand near her mouth and see if she will do the rest. Next just put her finger in the food and encourage her to lift it to her mouth. **Each time she does more for herself, praise her warmly.**

This method is part of a 'behavioral approach' to teaching new skills. The same approach can be used for teaching the child many skills related to eating, such as using a spoon or drinking from a glass. To learn more about this approach, see Chapter 41, "Ways to Improve Learning and Behavior,."

IMPORTANT: Try to **make mealtime a happy time.** Remember that it takes time for any child to learn new skills, and that a child learns best when he plays. When any child first learns to eat for himself, he makes a mess. Be patient, help the child to become more skillful at eating, praise him when he does well, but at the same time let him enjoy himself and his food. Remember, even normal children often do not learn to eat cleanly and politely untill they are 5 or 6 years old – or even older.



A cover or 'bib' like this, of plastic or waterproof cloth, is a big help. The pocket at the bottom catches spilled food.

While it is important not to push or hurry children too much in developing feeding skills, the opposite is also true. Often parents wait too long and do not expect enough from their handicapped child. On the next page is a 'trick' that a rehabilitation worker uses to help parents awaken to the ability of their retarded child to learn new skills.

THE 6 MINUTES BISCUIT TRICK FOR DEVELOPMENTALLY DELAYED CHILDREN

by Christine Miles, Mental Health Centre, Peshwar, Pakistan

The 'trick' gets parents to open their eyes to what their child actually can do and learn to do. I see many parents with developmentally delayed children between 15 and 30 months. They have realized that the child is not functioning at a level appropriate for his age. But often they cannot describe what the child actually can do, and do not seem to realize that children gain new skills by **learning**. Parents complain that "He doesn't speak. He can't do this, he can't do that, "as though there is something wrong with the machinery or someone has failed to push the correct button.

I ask them whether the child can eat a biscuit (cookie). "No, he only has milk and mush. He can't feed himself." I get a biscuit and put it into the child's hand. I guide the hand up to the mouth. Sometimes the child will bite on the biscuit; sometimes it needs to be tapped gently against his teeth and wetted with his lips and tongue until a piece breaks off and is eaten. I move the child's hand away from the mouth, then repeat the process. Usually by the time half the biscuit has gone, the child has learned how to do it, and finishes the biscuit happily without help. The parents usually say "Oooh!"





In 6 minutes the parents have watched their child **learn** an important skill, by our using a simple directed action and a strong reward (tasty food). Whether their child is temporarily delayed in development or will be permanently retarded, the parents gain some vital information about the child's ability to learn. Whether or not they remember anything else that I say to them, they go away with a whole new experience to think about. Almost always they have consulted several doctors before coming here, without gaining any useful advice.

Of course, it is not guaranteed to work. But it does work surprisingly often. The 6 minute biscuit trick is a powerful stimulant to parents to actually observe their child and to help the child learn.

SELF–FEEDING SUGGESTIONS FOR THE CHILD WITH CEREBRAL PALSY

CP

COMMON PROBLEMS

The less-used arm pulls up and back or moves about

Head twists to side and back.



Child has a weak, awkward grip, and poor control of arm movement

Whole body stiffens backward.

SUGGESTIONS

Help the child to control arm at shoulder.



Have the child hold his hand, first on a post, later on a dish.

Help him learn to hold the spoon firmly



WRONG BETTER



Straighten his hand by turning it out gently from the base of the thumb.

Sometimes you can help her with head control by gently pressing one hand flat against her chest.



A child who has difficulty controlling her hand for eating may gain better control by resting her elbow on the table.

Raising the table may make it easier for some children.



Where the custom is to eat sitting on the floor, a child may be helped by making a low table out of a box.



Sometimes you can help the child avoid twisting to one side by bending the less-used arm across the belly, and turning the palm up.

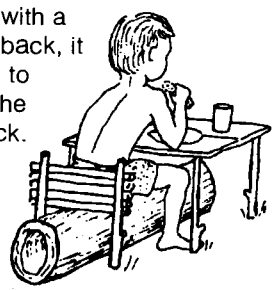
A child who has trouble controlling a cup with one hand can often do better if the cup has two handles.

Or you can make a frame like this by twisting thick wire. A glass can fit inside and the child can hold on. Wrap thin pieces of cloth around the handles for a better grip.

When head and body are difficult to control, it may help to sit on a bench or log in a 'riding' position.



If he sits with a rounded back, it may help to support the lower back.



Ask a local potter to make one.



Photo :Avijit Kishore



A wooden plate and glass stand keeps the plate and glass in place. It is helpful for a child like Arzoo who has difficulty in controlling the movement of his hands. **Photo :** Avijit Kishore

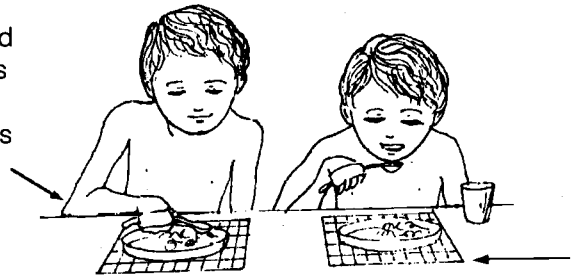


It is easier for a child who has difficulty controlling his movements to use a thali with high edges rather than a plate. The high edges of the thali prevent the food from spilling. The child can bring the food to the edge of the thali with the spoon or hand and then scoop it up. The thali is also useful for a child with visual disabilities. **Photo** : Avijit Kishore

Homemade equipment to help eating

A plate with steep sides makes eating easier for the child who uses only one arm. When that arm is very weak, it helps if the dish is low on one side and high on the other, to push food against.

The boy, whose arms and hands are paralyzed, lifts his spoon by raising and lowering his shoulder. His forearm is on the table edge, so that when he lowers his elbow, his hand lifts.



A non–slip mat under the plate can be made from strips of tyre tube woven over a stiff wire frame.

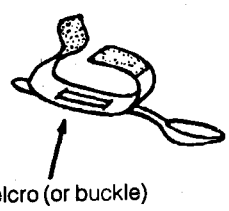


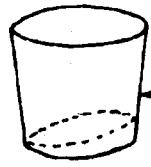
Photo : Avijit Kishore

This plate has been designed specially for children who may have difficulty scooping from an ordinary thali. The compartments here are designed in such a way that they slant downwards towards the edges of the plate. Liquid foods like dals and curries, will then keep collecting at the edges making it easier for the child to get a whole spoonful.

(For more details contact Spastic Society of Northern India, Delhi. (Address at the end of book).

The spoon slips into a leather or rubber (tire tube) hand band. (Also, see p.701).



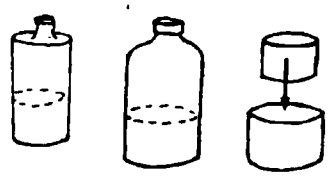


The special plate can be made from a small plastic bucket.



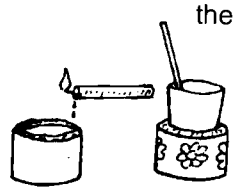
To prevent slipping, you can glue (with a waterproof glue) strips of tyre tube on the bottom.

A **non-spill cup holder** can be made using 2 plastic bottles.



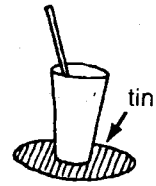
Fill space between containers with fine sand, plaster or cement.



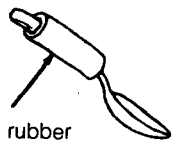


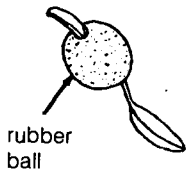
Seal with wax or waterproof glue.

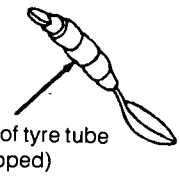
Or, glue a plate or tin to the bottom of the cup.

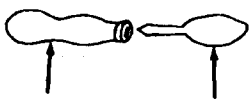


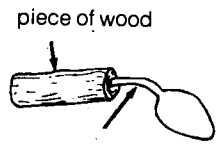
Spoon handles for easy gripping

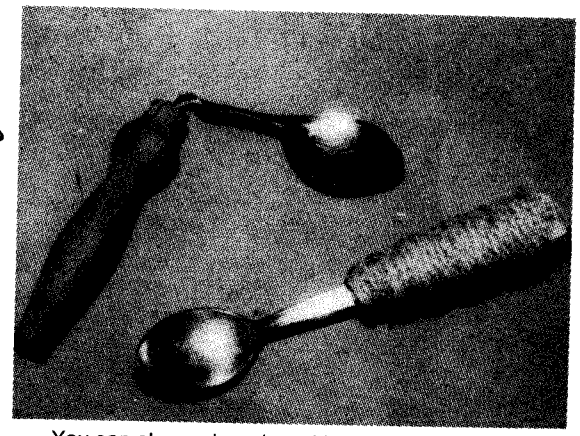








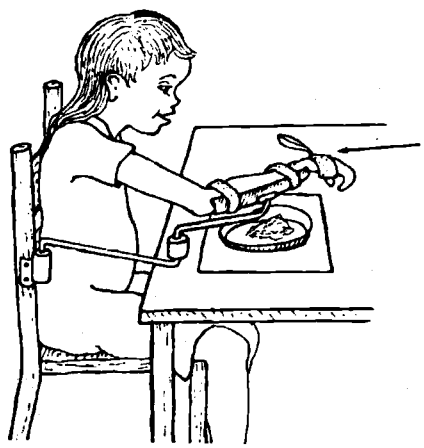




You can also make grips with wood or use coir or jute on handles to aid in grip
Photo : Avijit Kishore,
(Spastic Society of Northern India.)

Swing-a-sling eating aid

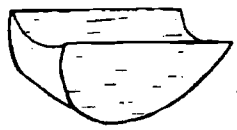
This eating aid lets a child with very little strength in her arm to feed herself. However, it must pivot smoothly but firmly at 3 points. It will take a skillful and imaginative crafts person to make it.



The spoon holder can also be adapted to hold a pen, brush, and other things.

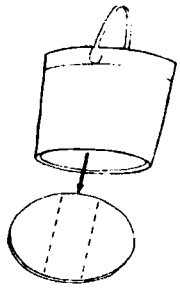
Arm rocker–for a child whose arm is too weak to lift

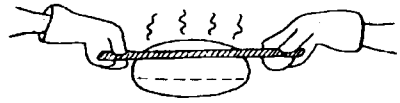
Carve it out of wood– or glue together layers of *'Styrofoam'* (stiff foam plastic) or cardboard.





Or make it from the bottom of an old plastic (or metal bucket.)





Heat the plastic along the lines with a hot strip of metal.

Strap may or may not be needed.



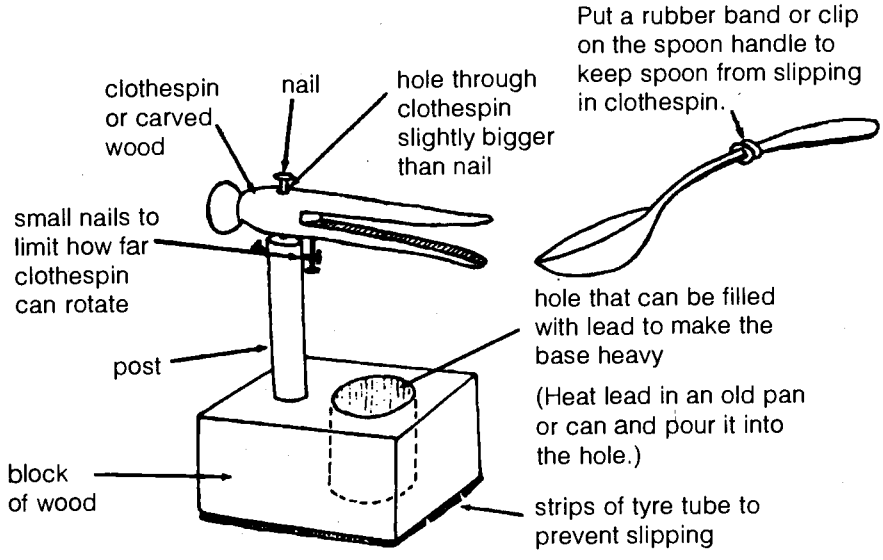
And bend it like this.





A boy with muscular dystrophy, whose arm is too weak to lift it to his mouth, eats with the aid of an arm rocker. This arm rocker, cut out of ***Styrofoam***, took about 5 minutes to make.

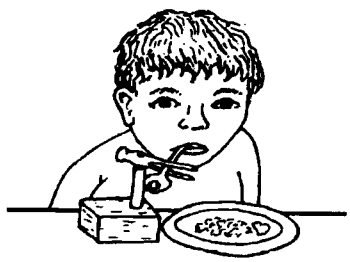
Feeding aids for a child with no hand use



Pick up food holding spoon in mouth.



Slip spoon into clothespin.

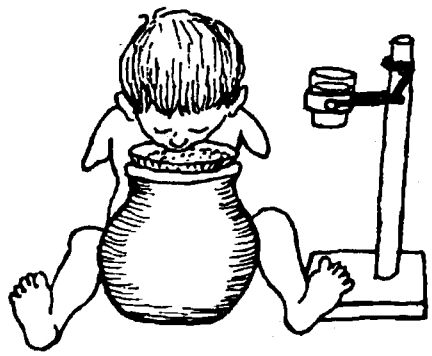


With the lips, turn clothespin so that spoon enters mouth.



Note: **If other children laugh at the child's awkwardness, let him practice alone until he gains some skill.**

Children with no use of their arms can feed themselves by lowering their mouths to their food. It helps if the plate can be lifted nearer to the face. A pot like this helps to stabilize the plate. If the plate has a rounded bottom, the child can tip it bit by bit as it is emptied.



A rack allows the child to drink from a cup that he can tip with his mouth.



Or simply use a straw.

Use your imagination **to think of many other ways to help the disabled child eat and do other things for himself.**

NOTES

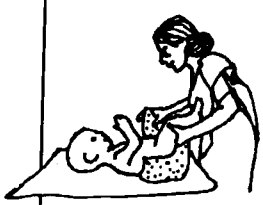
CHAPTER 38

Dressing

Children with ***disabilities***, like other children, should be encouraged from an early age to help with their own dressing. It is important, however, not to push a child to learn skills that are still too difficult for her level of development.

AVERAGE AGE WHEN NON-DISABLED CHILDREN DEVELOP DRESSING SKILLS

Under 1 year old Baby does not help at all.



1 year old Cooperates when being dressed.



2 years old Removes loose clothing.



3 years old Puts on loose clothing.



4 years old Buttons large buttons



5 years old Dresses alone except for difficult steps.



6 years old Ties shoe or adjusts sandals.



Children may learn dressing skills at different ages depending on local customs and on how much importance parents give to learning these skills. Observe what other children in your village or can do at different ages.Children may begin to take off their clothes before they are 2 years old, yet may not learn to put on all their clothes correctly until they are 5 or 6 years old. Often a normal 6-year old may put a shirt on backward, or the left sandal on the right foot.

Children who are slow in their development or who have difficulty with movements may be slower to learn dressing skills. It may seem quicker and easier for mother or sister to simply put the clothes on her, without interacting with the child. However, this will only delay the child's development more.

It is important to **use dressing as an opportunity to help the child develop in many areas at once: awareness, balance, movement, and even language.**

As you dress the child, talk to her. Help her learn her body parts, the names of clothes, and the way these relate: "The arm goes into the sleeve," "The foot goes into the pants," and so on. This will help the child begin to learn language and connect parts of her body to her actions and things around her.



For a child who cannot see, help her first to feel and recognise the different textures of the clothes she wears. This will help her to recognise material and also her own and other people's clothes. Talk to her while you dress her and tell her what you are doing. Later you can help her feel different parts of the garment she wears. Slowly she can start taking an active part while dressing.

Helping the child gain dressing skills takes time and patience. Let her try to do as much as she can for herself. Be ready to help if it gets too difficult, but only as much as is needed. It is not good to frustrate the child so much that she will not want to try again. Be sure the task is not too advanced for the child's level of development.

(CP) POSITIONS FOR DRESSING

Try dressing the child in different positions, to see what works best.

Body position is especially important when dressing a child with spastic cerebral palsy. Often his body tends to bend stiffly backward if he is dressed lying on his back.

A bad position:

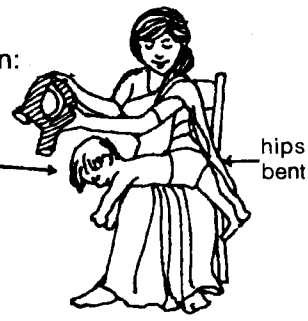
(child's body stiffens backward)



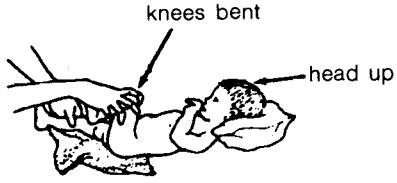
Hand bends tightly.

It often works better to dress a child with ***spasticity*** with his body and hips bent forward.

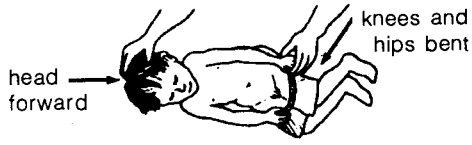
A good position:



For changing that needs to be done **face-up,** try putting a firm pillow under the head, and keep knees and hips bent. This may help the baby relax and not stiffen up.

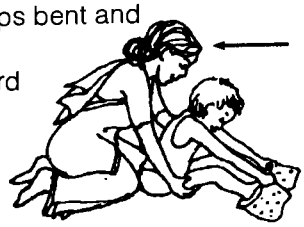


Lying on the side is often a good position for a child with spasticity who is beginning to dress himself. In this position, the child can see what is going on. It is easy to part the legs and bend them. It is easy to bring the arms forward and straighten them to put the sleeves on. The child may need to roll from one side to the other to pull on clothes, but he should keep his knees, hips and head bend to avoid stiffening.

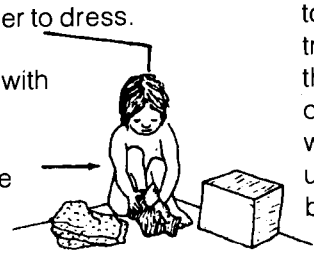


Dressing is often a once a day activity in most households. If a child is only partially independent or totally dependent on others for dressing, parents sometimes feel that this is one activity they can manage. In such instances, it is still important that parents stress the right positions for a child. Not only will it make their task easier, but it is also therapy for the child.

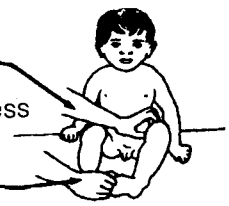
To help the child **dress while sitting,** be sure he is in a steady position. You can help him keep his hips bent and body forward like this.



If the balance when sitting is still not good, or if the child tends to stiffen backward, try sitting in a corner to dress.



Sitting with the feet forward and knees apart is a good position for play and dressing. If legs press together stiffly, try pushing the knee out gently while you press under the big toe.



When a child with athetoid cerebral palsy tries to raise her arms or to speak, her feet may come off the ground or her legs spread. Try pressing down over the knees, keeping them together. Or press on top of the feet.



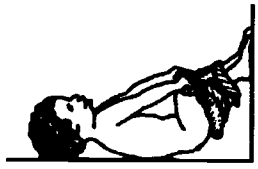
Sitting cross legged gives the child the stability she needs to wear her frock. Place the frock in such a way in front of the child that she first puts on the sleeves. Then it is easier for her to put her head through the neck hole.



When she wants to take off her frock she will first pull the frock over her head. And then pull her arms out of the sleeves.



Help the child find the position that allows the best control for dressing.

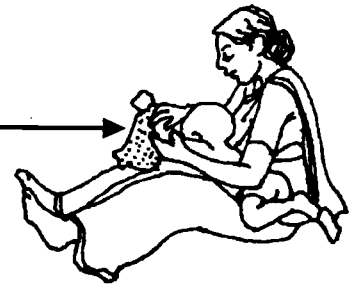






SUGGESTIONS FOR DRESSING

- If one arm or leg is more affected than the other, it is easier if you **put the clothes first on the affected side.**

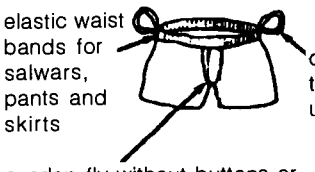


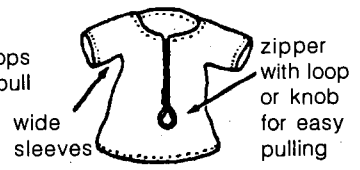
- Put the clothes where the child can see and reach them easily, so he can help in any way possible.
- If the arm is bent stiffly, first try to **straighten it slowly,** then put the sleeve on. (If you try to straighten it forcefully or quickly, it may become more stiff.)
- If the legs straighten stiffly, bend them gently in order to put on pants or shoes.



- Begin any dressing activity for the child, but let him finish it for himself. Little by little have him do more of the steps. If he can do it all by himself, give him time. Do not hurry to do it for him if he is struggling to do it himself. Praise him when he does well or tries hard.

- **Use loose-fitting, easy-to-put-on clothing.** It is not always possible for parents to buy new and special clothing for their child. Most adaptations can just be made on clothes we normally wear. All of us have grown up wearing "hand me downs" from our brothers and sisters. Often these clothes"Just fit" and that may not be appropriate for the disabled child. So families and the community need to look for other solutions. A young spastic boy of thirteen may find his father's or his uncle's shirt or pullover easier to wear than his brother's! It is also helpful if clothes are made out of thin but strong material. Thick cloth is more difficult to put on.

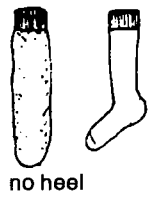




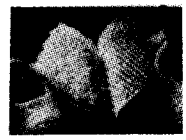


Large boat shaped neck lines for blouses and shirts without buttons.

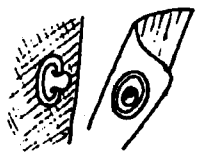
'Tube socks' (socks without heels, that stretch to fit foot) are easier for the child to put on.





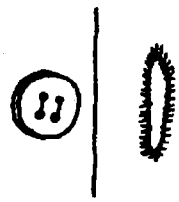


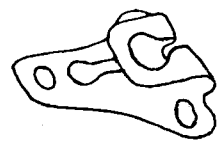
Remember, never to iron on velcro tabs with a hot iron



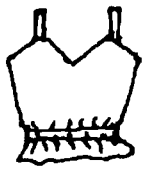
Press-together studs (snaps) are easier to open and close than buttons.

If buttons are used, use large buttons and make buttonholes extra big.



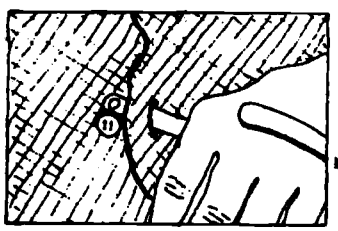


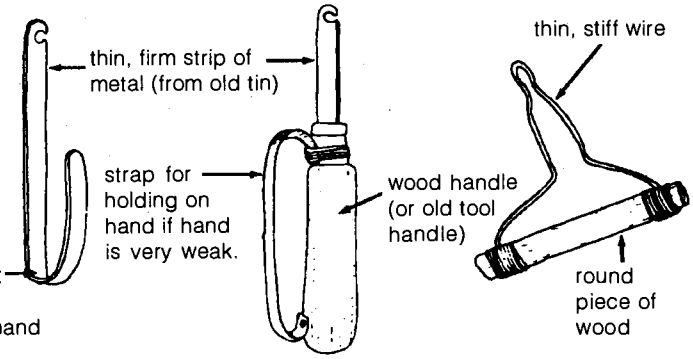
Large metal hooks such as these are easier to use than small ones



This slip on bra has no clasps and can be used quite effectively by a girl who can use only one of her hands. She can slip the bra over her head and with her good hand, put the strap through the affected hand. She can then pull the strap through her good hand and pull the bra down. The bra has an elastic which fits below the breasts.

- For children who have poor finger control, make a simple tool to button and unbutton buttons.

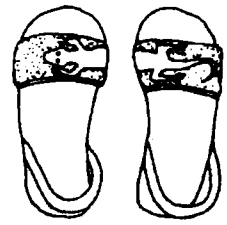




- For the child who often puts her dress on backward, or her sandals on the wrong foot, try to build in 'reminders' that will help her do it right. For example:

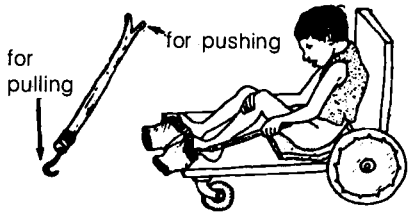


Sew a colorful bow on the front of her dress. This would also be useful for a child who cannot see.

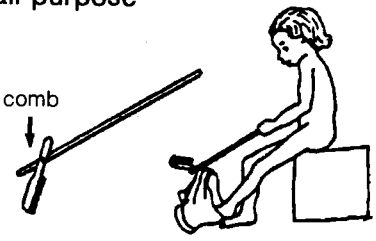


Draw half an an animal on each sandal or shoe so that the 2 halves make the whole animal when she puts them on right.

- For the child who has difficulty reaching his feet, a **stick with a hook** may help.



An all-purpose tool





- Raisa is severely affected with cerebral palsy. She finds it difficult to eat, dress or bathe without being helped at every step by her mother. Raisa cannot speak and till quite recently, she would communicate with gestures that only her family understood. But one day she got a communication board with all the words that would help her 'talk' to her friends and teachers.

  The first wish that she communicated to her teacher was that she too wanted to dress up. She wanted to wear a nice coloured *salwar kameez* instead of the drab loose ones she always wore. She wanted to wear pretty *dupattas* which she had never worn. Raisa wanted to look good.



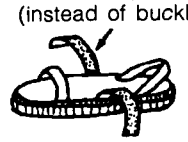


- **All children, (whether disabled or not) love to dress up. Sometimes, the disability of a person may be so overpowering that people around her may not recognise her need to look good. But this may be extremely important for her self image.**

Ideas for shoes

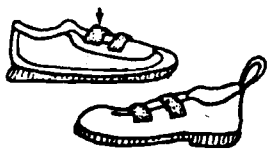
- For toes that claw up, or bend under, you can cut off the top of the shoe, or use a sandal.

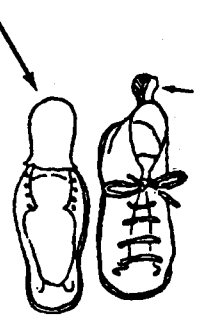




- Tennis shoes or other shoes that open all the way down to the toes are easier to put on.

Velcro straps for easy fastening can make many children more independent in dressing.





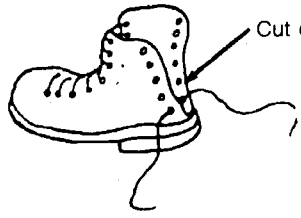
A leather or cloth loop sewed on the heel makes it easier to pull on shoe.

Consider using shoes that fit loosely–about one size too large.

Shoes with elastic laces are sometimes easier to put on than shoes with laces.

- If the foot stiffens downward so much it is hard to get a shoe on, you can cut the back of the shoe open and put the foot in from the back.





HOW TO TIE SHOES WITH ONLY ONE HAND

1.



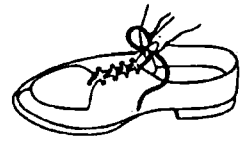
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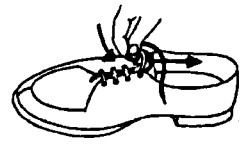
3.



4.



5.



6.



For special footwear designs for feet that do not feel, see p. 265 and 267.
For shoe adaptations for braces, see p. 664.

CHAPTER 39

Toilet Training

By **'toilet training'** we mean **helping a child learn to stay clean and dry.** A child is toilet trained when:

- He knows when he needs to pass stool or urinate and has learned to 'hold on' so he does not go in his clothing or on the floor (***bowel*** and ***bladder*** control).
- He tells people when he needs to do his toilet,
  or (if he is physically able)...
- he takes himself to a special place (pot, toilet, latrine, or at least outside the house), removes necessary clothing, 'goes', cleans himself in the customary way, puts his clothing back on, and does whatever may be necessary to get rid of the waste.



'Toilet training' is important for the development of a child's independence and dignity. Yet it is very often neglected in disabled and *retarded* **children.** Often we see children 5, 10, even 15 years old who are still in *diapers (nappies)* and who are still completely dependent on their mothers for being changed and cleaned. This situation is hard on both child and family. With a little instruction and encouragement, we have found that many of these children have become ' toilet trained' in a few days or weeks. Many could have learned years earlier.

The age when normal children become toilet trained varies greatly from child to child. It also varies from place to place, according to local customs, what clothes children wear (if any), and how much the family helps. With training, many children can stay dry and clean by age 2 or 2 1/2. With little or no training, most normal children learn to stay clean and dry by age 4.

Children who are developmentally slow, or physically disabled, are often late in learning to stay clean and dry. This may be partly due to **their disabilities.** But often it is because the **parents have not provided the opportunity, training, and help** that the child needs. For example, one mildly retarded blind 16 year–old boy, still depended on his mother to change his diapers. His mother had never seriously tried to teach him and thought he could not learn. Yet with a little help from a *rehabilitation* worker, he became completely toilet trained in 3 days!

Handicapped children should be helped to become as independent as possible in their toileting. With help, **most retarded or disabled children can learn to indicate by ages 3 to 5.**

Of course, children with ***severe physical disabilities*** may always need help with clothing or getting to the pot. But they can learn to tell you when they have to go, and do their best to 'hold on' until they are on the pot.

Children who lack bladder and bowel control because of **spina bifida** or **spinal cord injury** have special problems. But even these children can often learn some control and become relatively or completely independent. The special problems and training of these children are discussed in Chapter 25.

WAYS TO MAKE TOILET TRAINING EASIER

1. Start when the child is ready

Just as training should not be delayed, it also should not be started too early. If a child's body is not yet able to control her bladder and bowel, trying to train her can lead to failure and frustration–both for the child and her parents. Normally a child is 'ready' by age 2 or 2 1/2. But in some children, training may need to be delayed to age 3 or 4, or sometimes later.

There are **3 simple tests to check if your child is 'ready' for toilet training.** These are: bladder control, readiness to cooperate, and physical readiness.*

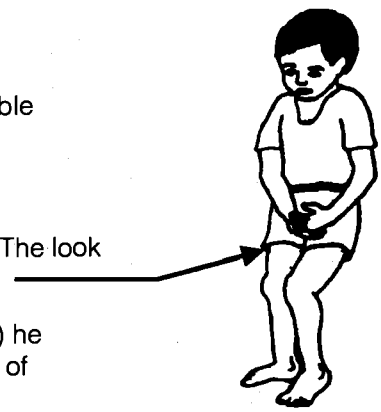
- **Bladder control**

  Does your child urinate a lot at one time and not dribble every few minutes?

  Does he often stay dry for hours?

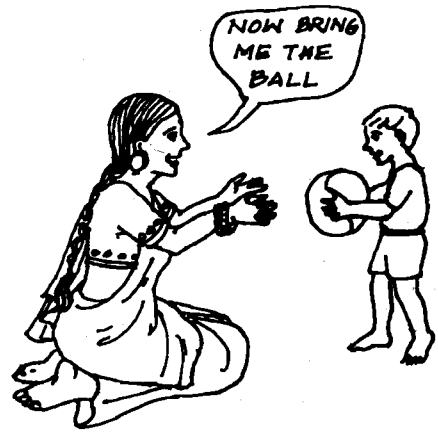
  Does he seem to know when he is about to urinate? (The look on his face, holding himself between the legs, etc.)

  If the child does these 3 things (or at least the first 2) he probably has enough bladder control and awareness of urinating to make training possible.



- **Readiness to cooperate.** To test whether the child has enough understanding and cooperation, ask her to do a few simple things: lie down, sit up, point to parts of her body, put a toy in a box, hand you an object, and imitate an action like hand clapping. If she does all these things willingly, she is probably mentally ready for toilet training.

- **Physical readiness.** Can the child pick up small objects easily? Can she walk or move herself fairly well? Can she squat, or sit on a stool, and keep her balance? If so, she is probably physically able to do her toilet by herself. if not, she can probably still be trained but may need physical assistance and/or specially adapted aids.



Most children more than 2 years old can pass these 3 tests. If not, it is usually better to wait before trying toilet training, or to help the child become more ready.

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* These tests and many of these suggestions on toilet training are adapted from *Toilet Training in Less Than a Day.* Azrin and Foxx. Pocket Books, N.Y. 1974.

SPECIAL PROBLEMS

If the child still **does not have enough bladder control or awareness,** it is best to wait until she is older. For example, some children with cerebral palsy are slow in developing bladder control. (CP)

If the child **does not hear or understand simple language,** or is mentally retarded, more of the training needs to be done by ***showing*** and less with words. Special gestures or 'signs' need to be worked out for 'wet', 'dry', 'dirty', 'clean', and 'pot' or 'latrine'. Instead of teaching by using a doll, it is more helpful to have another child demonstrate toilet use.

If the child is **stubborn, refuses to cooperate** when asked to do simple things, or often cries and screams whenever he does not get what he wants, toilet training will be more difficult. Stubbornness and refusal to do what they are told are common in many handicapped children–mainly because they are often overprotected or spoiled. Before trying to toilet train such children, it is wise to work first on improving their attitude and ***behavior.*** This is discussed in Chapter 41.

If a child's **physical disability** makes it difficult for her to get to the toilet place, to lower her pants, to squat or sit, or to clean her bottom, various aids or ways must be looked for to help her become as independent as possible. These will be discussed on the next pages. (CP)

> ***CAUTION:*** Children with cerebral palsy who have very tight spincter muscles may take time to relax enough for the urine to come out. There may be a special position in which the child feels secure and is able to perform is a relaxed manner. (CP)

Sometimes it happens that the child indicates to the mother–the mother puts him on the potty — the child does not perform — the mother hurries the child up — he still does not perform — the, frustrated, mother puts the child on the bed — and the child performs. This may lead the mother to feel that the child is purposely behaving badly. But actually

- The child may be unable to relax in the position he is put in.
- The child may need more time to relax his muscles.

It is important for parents to explore these possibilities before deciding that he has a behavior problem.

2. Put the child on the pot at the times when she is most likely to use it

Before beginning toilet training, for several days notice at **what time of the day** the child passes stool and urinates. Usually there will be certain times when she usually does so–for example, soon after the first meal of the day.

Begin to put her on the pot or latrine at these times, encouraging her to make 'poo' or 'pee' (or whatever she calls it).

Leave her on the pot until she 'goes'– or for no more than 10 minutes.

Keep the pot or latrine at the same place all the time so that the child gets used to one particular place.



If the child 'goes', clap your hands, kiss her, – and let her know how pleased you are.

If she does not 'go', just ignore it. Do not scold or make her feel bad, or she may begin to fear or dislike the pot, and refuse to use it.

3. Reward and praise success

In toilet training–as in any form of education— it works better **to reward success than to punish failure.** When the child passes stool or urinates where she should, give her praise, hugs, kisses and other signs of approval. However, **make sure that the child knows you are pleased with her,** not because she passes stool and urinates, but **because she is staying dry or clean.** When training, check the child often to see if she is 'dry' or 'clean'. When she is, praise her. Also, teach her to check herself.



When the child has 'an accident' and wets or dirties herself **do not punish or scold her.** It is better to quietly clean up the mess or change her. At most, say something friendly (but not approving) like, "Too bad!–Better luck next time!"



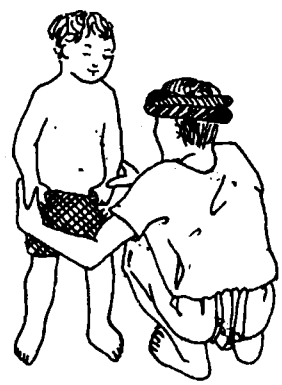
DO NOT GIVE FOOD AS A REWARD TO CHILDREN WHO ARE FAT

CAUTION: As general rule, do not offer a child candy, sweets or other food as a reward for doing something right. This can lead the child to associate food with love or approval–and therefore to make constant demands for sweets. Avoiding food rewards is especially important for children whose disability makes them less active, so that they easily get fat. Extra weight makes moving around harder for both child and parents. SO.....DO NOT LET DISABLED CHILDREN GET OVERWEIGHT.

For children who are thin and active, it may make sense to sometimes give foods as rewards. But be sure to include healthful foods like nuts and fruits–not just sweets.

4. Guide the child's movements with your hands–not your tongue

When the child has difficulty carrying out a physical task–for example, lowering his pants–do not do it for him (if it is something he can learn to do for himself). And do not tell him his mistakes or how to correct them. Instead, gently guide his hands with yours so that he learns how to do it himself.



guiding the child's hands

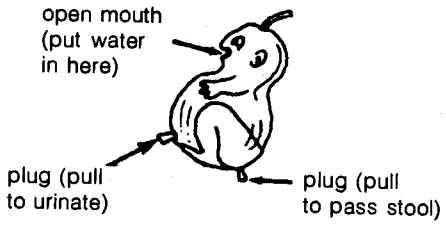
5. Use models, examples, and demonstrations

Setting an example is one of the best ways of teaching–especially if the example is set by persons the child loves, admires, and tries to copy. Even before children are old enough to be toilet trained, help prepare them by letting them watch their brothers and sisters use the pot or latrine. Tell them that when they are big enough they will be able to do it that way too.

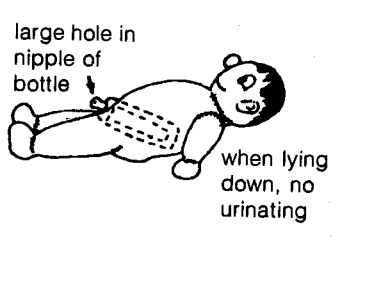


Using a **doll that wets** is another good way to introduce toilet training. Dolls that 'wet' can be bought, or you can make one out of,

a gourd

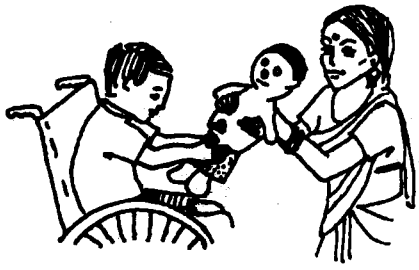


or a baby bottle inside a homemade rag doll.

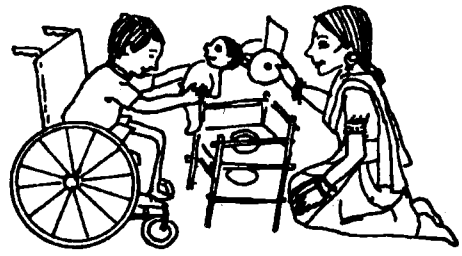


Show the child how the doll urinates in the pot. Or better, ask your child to help you toilet train the doll. Be sure to include each step that will be needed for the child to become as self-reliant as possible. For example:

First have the child show the doll how to get to the latrine or pot–and then help the doll lower his pants.



Next have the child teach the doll how to get onto the pot, and sit there until he urinates. Try to make the situation as nearly like that of the child as you can–using the same pot in the same place that he will use it.



Turn it into a game, but keep the focus always on toilet training



After the doll has finished urinating, have the child pull up the doll's pants. Ask him to feel the doll's pants and check whether they are dry. If so, have him praise the doll.

To repeatedly see real persons (not just dolls) ***enjoy*** and be rewarded for using the pot or toilet is especially important for a child who is retarded or who has language difficulty.

6. Adapt toileting to the special needs of the child

Many handicapped children can be helped to become independent in their toileting if special aids or ***adaptations*** are made. Different children will require different adaptations. However, the following are often helpful:

- If the child has trouble pulling down pants or panties–**use loose fitting clothing with elastic or *'Velcro'* waist band.**

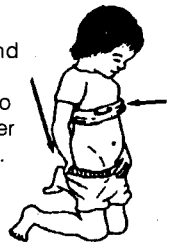
Correct position of hands, for lowering pants

Hook thumbs inside pants and push down



for raising pants

Put hand inside pants to pull over bottom.

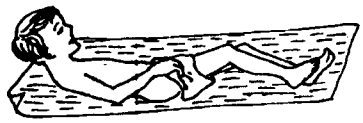


For training, pin shirt up out of the way– or do not wear one.

- Use short 'training pants' made of towel-like material that will soak up urine.



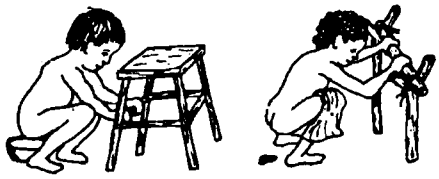
- For a child with cerebral palsy or spina bifida, it may be easier lying down–you might provide a clean mat.



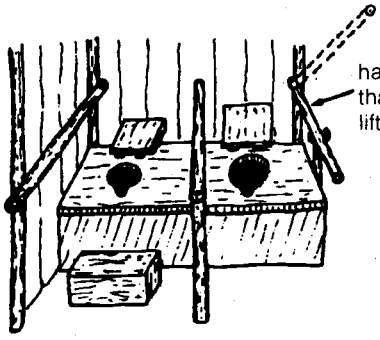


Some children, like this girl with cerebral palsy, need to sit. This potty seat was adapted from a child's wood chair.

- If people by custom squat to pass stool, and the child has trouble, a simple hand support can help.



- Latrines can also be adapted.

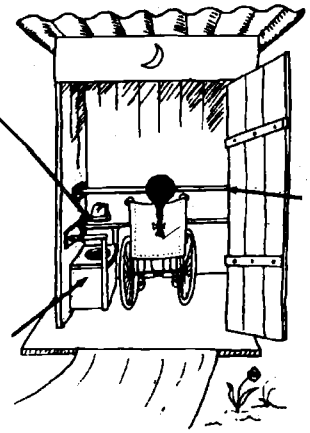


hand rail that can lift up

2-seater latrine with child-sized hole and step

arm or shoulder supports close to the toilet

toilet seat and wheelchair seat on same level



high hand rail to make moving from wheelchair to toilet easier

Make the outhouse (latrine) and its door big enough so that a wheelchair can fit inside. Position the door so that the wheelchair can enter right beside the latrine without having to turn around.

Be sure the path to the latrine is level and easy to get to from the house.

- A simple pot or 'pottie' is one of the best aids for toilet training of young children. it can be adapted in various ways for disabled children

Simple pot



more complex pots sold in some countries



These give good back support.



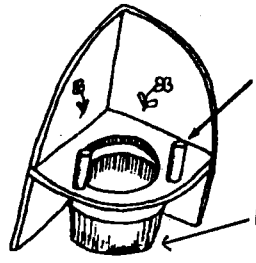
'Baby Relax Toilette' with removable pot— gives good back and side support.



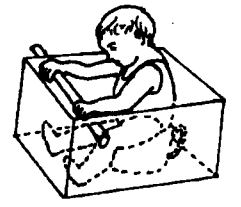
For the child severely disabled with cerebral palsy, the pot can be placed between mother's knees. This provides good back support. Mother holds his shoulders forward, his hips bent and his knees separated.



Later it may be possible to put the child on a corner seat like this— which also holds arms and shoulders forward and helps keep hips bent.

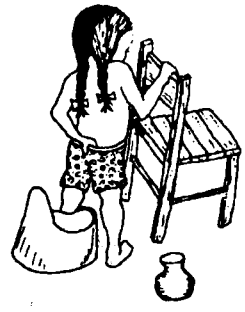


A cardboard box can also make a good sitting frame.



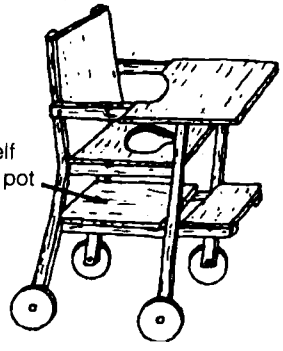
Use your imagination and whatever materials you can get to make it easier for your child to do it by herself.

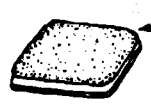






For severely handicapped children, 'toilet seats' can be built into specially designed chairs.





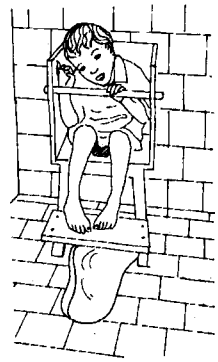
A cushion can be made to fit over the toilet seat for ordinary sitting.

Put a shelf for the pot.



Or leave the space under the seat open, so that the whole chair can be rolled over a toilet.

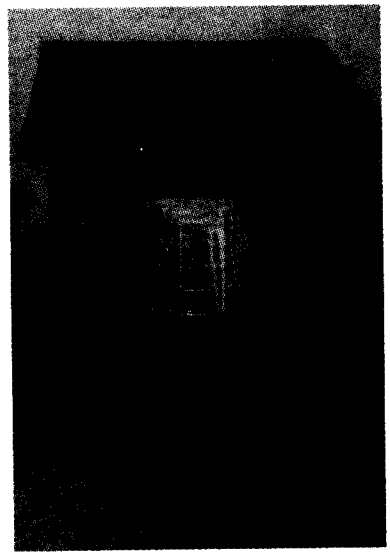
The Indian toilet can be adapted for use by placing a low box seat or a low stool with a hole in the centre. The child's feet should be flat on the floor.The child can have a bar support to hold on to in front. The bar support should be fixed so that it can be raised when not in use. (From Guidelines on Cerebral Palsy).



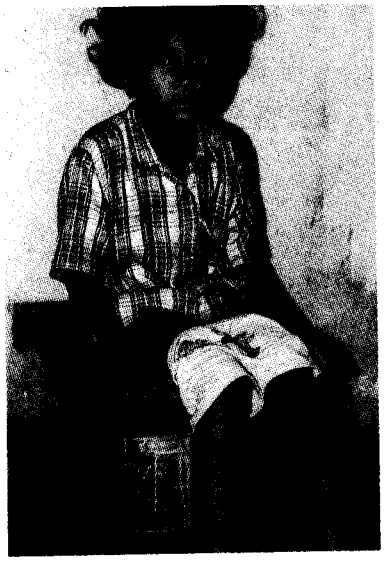
Photos: Spastic Society of India, Bombay.

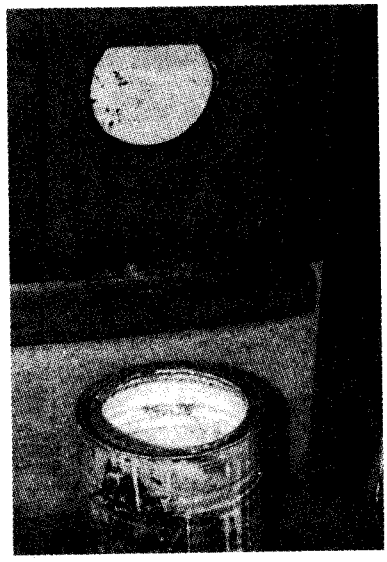


It was Sahiba's mothers idea to use an old unused broken charpoy as an adapted potty for her Sahiba who has polio. A few more strings from the charpoy were cut to accommodate Sahiba. A newspaper sheet is placed below the cut end to enable easy cléaning and disposal.



An older child can be given an old discarded stool with a hole cut in the centre. A paper or an old tin placed below the seat enables this to be used inside a home and outside. This adaptation is being used by many disabled children in the slums of Dharavi, Bombay. Designed at Karuna Sadan, Spastics Society of India, Bombay.





Urmila uses this toilet adaptation with an old tin placed below for easy disposal. The major problem encountered in homes at Dharavi (a big slum in Bombay) is lack of space. A folding toilet seat was made which could be attached to the wall. It was made with locally available sturdy wood with a hole in the centre of the seat. One end of the seat was attached to the wall and the other TST had collapsable stands. The seat opens to form a small stool.

For the child who cannot sit up, you might make a wedge-shaped toilet box like this.



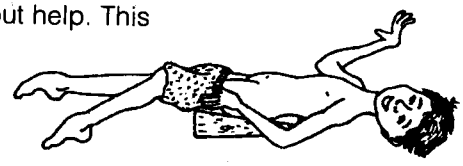


It works as a 'bedpan',

An old plastic bucket can be cut at the same angle as the bedpan so that it fits snugly under the hole.



or as a 'floor pan' for the child who can roll or scoot but cannot sit or lift himself without help. This way the child can learn to take care of his own toilet.



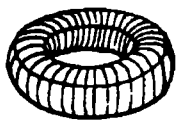
CP For the child who has ***spasticity*** or poor balance, you can make a seat like this. The bar can be put in after the child has been seated.



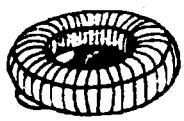
The seat can be made to fit over a bucket, over a floor-hole latrine, or over a standard toilet.

Tyre potty seat–soft, safe, washable*

Tyre can be used alone,

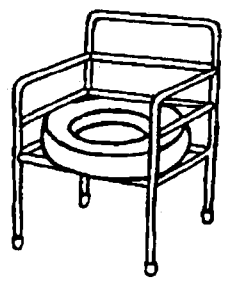


or over a 'hole-in-the-floor' toilet,



To keep urine from getting inside the tyre, you can wrap long strips of inner tube tightly around the tire.

or on a wood or metal frame over a toilet seat.



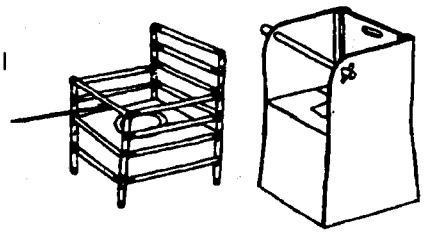
Try to pick size of tyres to match the size of the child. For small children, scooter or very small car tyres may work well.

* Ideas from UPKARAN manual. See p. 774

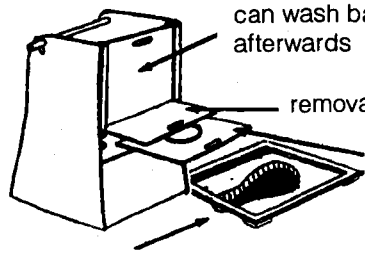
For many severely handicapped children who cannot sit on the potty by themselves, a urine bottle is very helpful. As soon as the child indicates, the mother can hand him the urine bottle to use. This prevents the mother from having to carry the child to the potty every time he wants to urinate.

Cane or rattan toilet set with climb up bars*

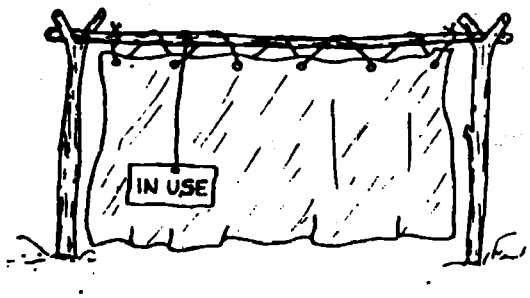
Or seat can I placed over hole-in-the floor toilet.



Enclosed wood or plywood toilet*



Or seat can be placed over a hole - in - the floor toilet.



REMEMBER: As the disabled child grows, she will feel the same need of privacy as any child would for toileting and other personal acts. **Help the child to obtain the privacy she needs.**



In the villages of Haryana, the chullah (cooking place made of bricks and mud) is used successfully as a potty chair for a child who can sit but cannot squat.

Photo : Avijit Kishore

* Ideas from India–UPKARAN manual. See p. 774.

CHAPTER **40**

Bathing

Regular bathing is important for all children. Bathing the severely disabled child, however, is often not easy. Children whose bodies get stiff or whose knees pull together may be very difficult to clean. As the child gets older and heavier, the difficulties often increase. Here are some aids and ideas that may make bathing easier. (CP)

For the baby or small child, some kind of a tub may be a big help.



A rectangular tub of the size you need can be made out of mud or mud bricks (or dried bricks) and covered with a thin layer of cement.

IMPORTANT: Talk or sing to the baby as you bathe her. Tell her each thing you do, and the name of each body part you wash, even if she cannot understand. A child must spend a long time listening before she can say her first words. So **get an early start.**



This is a good way to hold the child who stiffens and bends backward or throws open her arms when you pick her up. (CP)



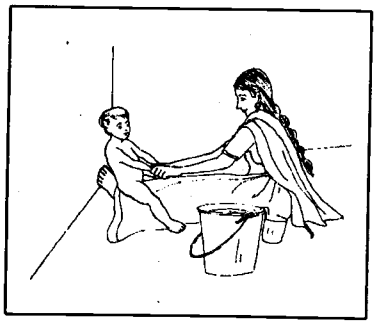
This traditional way of bathing can be effectively used for a baby with cerebral palsy. The arms of the baby are placed forward and the legs, prevented from pressing tightly together by the mothers own feet.



Then place the child on his back, gently spreading the legs as wide as possible to clean between them. Also, lift arms above the head. In this way, **bathing can be combined with range-of-motion exercises.**(see chapter 43)

A baby that tends to stiffen backward can be held bathing.





An older child can be seated on his mother's feet supported by the corner of the bathroom. (CP)

Our goal in bathing is SELF-CARE, even for the child who is fairly severely disabled or retarded.

For many children **balance is a problem**, even while sitting. Anything that can help the child keep his balance, and stay in a position where he has the most control, will help make bathing easier. **Here are some aids and suggestions for helping the child manage better.**

The child who has trouble sitting because she stiffens backward may need some kind of back support to sit while bathing.



CAUTION: Be sure water is clean and does not spread disease.

2 old car tyres (or inner tubes) tied together



Note: Anything that keeps the hips bent up like this will help keep a child with ***spasticity*** from stiffening and bending backward.

Especially for the child who does not have good ***bowel*** or urine control, it is very important to carefully clean her ***bottom*** and between her legs. An inner tube on poles, like this, holds her in a good position for washing.



A child who can sit, bathe by himself on a cement floor can bathe in a sitting position in the corner. If in a bathroom, he should be sitting on a non slip mat. Two wet towels placed one on top of another can make a good substitute.

The bucket, soap, towel and mug should be within easy reach. Grab bars or rails can be added on the wall if the child needs help in getting up. Even a child who cannot sit, can be on the towels while being given a bath. This way he will not slip on the wet floor.

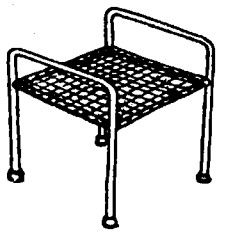


a bath seat made from half a plastic bucket or laundry basket on a tube frame.



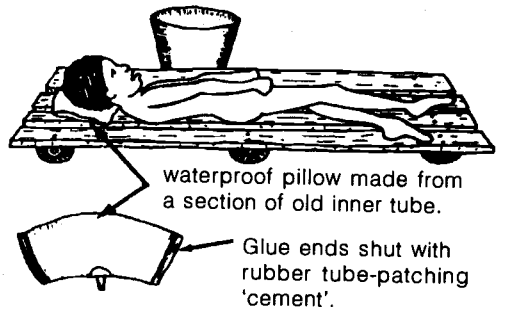
heat the edges to bend them around the tubing

a stool with a seat woven from strips of car tyre inner tube.



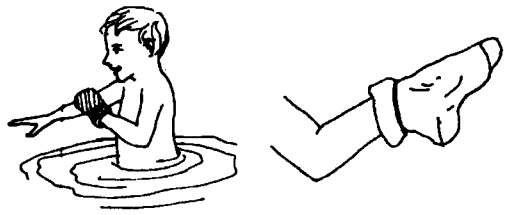
From the UPKARAN manual, See p. 774)

a washing platform of wooden slats for the child who washes (or is washed) lying down.



Also see the bicycle inner tube mat on p.234.

A soap mitt, made of a piece of towel and a tie string (or Velcro straps) lets the child who as difficulty grasping use both the washcloth and soap more easily. You can also use an old clean cotton sock as a soap mitt.



Bath time is a good time to help a child develop many different skills. Encourage her to handle and play with toys in the water, repeat words, and imitate actions. Let her feel the difference between a sponge and a cloth, or dry and wet and soapy. To learn to use both hands together, let her squeeze water out of the sponge.

To help the child learn how to bathe herself, let her first wash her toys and dolls. Show her how and encourage her to copy you.

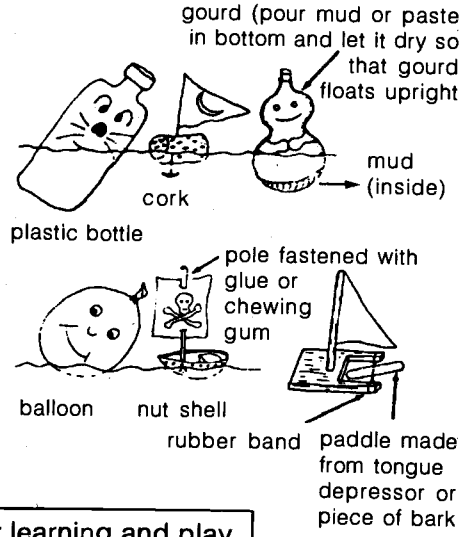


For a child who is afraid of water, letting her bathe a doll or a toy first may calm her fears.

If the child is bathing in a tub, use corks, bits of wood or plastic bottles with lids on them to make toys that float. Making little boats with sails or 'paddle wheels' makes it more fun and helps the child learn to use her hands better. The child with weak lips who drools can play by blowing a boat across the water.

For the child with limited control or strength, it is often easier to play in the water with toys that float than it is to play with toys out of the water.

Drying the child can also become a game that aids development. Rub the child, sometimes gently and sometimes briskly, with a rough cloth or towel. Name the different parts of her body as you rub them. Remember as you bathe and dry the child, talk about each thing you do— or sing a song about it! Move the towel with the music, and encourage the child to move with you. Use your imagination to make it more fun and to help her learn.



Use bath time as an opportunity for learning and play.

CARE OF THE TEETH AND GUMS

Many disabled children develop problems in their teeth and gums. There are many reasons:

- In children who have poor mouth and tongue control, food often sticks to gums and teeth and is not cleaned away by the natural movement of the tongue.
- Many disabled children (even those with no eating problems) are fed soft, sticky 'baby foods' long after they should be eating rougher, more solid 'adult foods'. So their gums get soft, weak and unhealthy.
- Sometimes children with *disabilities* are 'spoiled' by giving them extra sweets – which increases tooth decay.
- Some medicines for fits (epilepsy) cause swollen, unhealthy gums.
- Dental care is more difficult in some disabled children-especially those with cerebral palsy (In some places, dentists refuse to care for these children).

For these reasons, **we must take care to keep the gums and teeth of the disabled child healthy and clean.**

STEPS IN CARING FOR GUMS AND TEETH

1. **Avoid foods and drinks with lots of sugar** – especially between meals.
2. **Start child on solid food as early as he can take them.** – Toast,crackers,carrots, raw fruit and other foods that rub the teeth and gums clean are especially helpful.
3. **Clean the child's teeth and gums**, if possible after every meal. But if you can do it once, then do it before sleeping at night.

Before the baby has teeth, clean his gums with a soft cloth over your finger. First dip the cloth in boiled water with a little salt or baking soda in it.

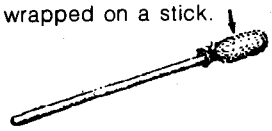


This is a good position to clean the child's teeth and gums. Be sure the head bends down.



If his head bends up, he will be more likely to choke or gag.

After the child has teeth, clean them with a small, soft toothbrush. Or use a piece of thick cloth or a bit of towel wrapped on a stick.



Or use a stick from a Neem tree or other non-poisonous plant

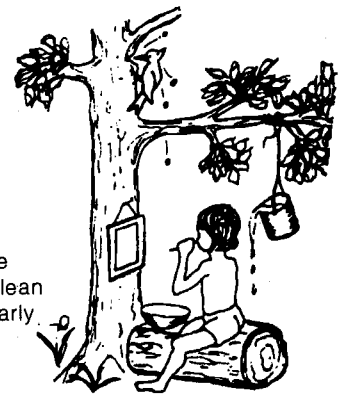


Sharpen one end to form a 'toothpick'

Crush the other end to form a 'brush'.

Toothpaste is not necessary. Instead you can use salt, salt mixed with baking soda, or a burned and powdered piece of bread, chapati or just water.

Clean all surfaces of the teeth well, and also rub or brush the gums.



4. Help the child learn to do whatever she can to clean her own teeth and gums. At first you can guide her hand, then have her do a little more each time, and praise her when she does it well.

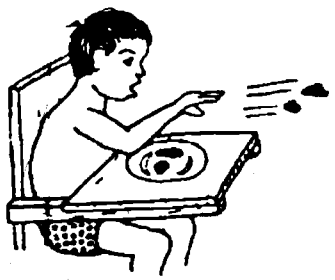
The child will be more likely to clean her teeth regularly if you have a special place, adapted to her needs.

***REMEMBER*: Brushing the gums is just as important as brushing the teeth.**

For more information, see ***Where There Is No Dentist***, Chapter 5, "Taking Care of Teeth and Gums" (see p.769).

CHAPTER **41**

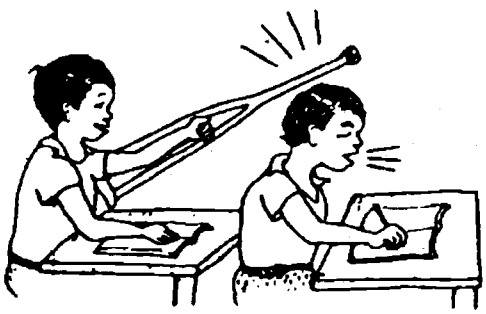
Ways to Improve Learning and Behavior



"I still feed Rahul myself because when I let him try to eat by himself he throws his food all over the place. The more I punish him the worse he gets. So I end up feeding him everytime".



"Sonu begins to cry and scream every time I put her down for a minute. It's worse when I take her out where there are other people. At the river she has such tantrums that I can't finish washing the clothes. At the market place she continues to scream until she gets what she wants".



"George is always starting fights with other children or doing other bad things–at home and in school. He seems to enjoy making people mad at him !"



"Ahmed just refuses to obey. He turns a deaf ear to whatever we tell him to do. It is very difficult to get him to do anything."

These and other **behavior** problems can occur in both non–disabled and disabled children. But some disabled children have special difficulty learning acceptable and appropriate behavior. Children who are **mentally retarded** may develop poor behavior because they are confused by the unclear or conflicting messages they get from their parents and others. Children who are **physically disabled** sometimes act in 'naughty' or self–centered ways because they have become dependent on others to do things for them. They lack self–confidence, and are not afraid of being forgotten. On the other hand, children who are often neglected or ignored when they are quiet and behave well, may learn to behave badly to get attention. Behavior problems are reported to occur three to four times more in people with disabilities than in normal people.

As a rule, **if children repeatedly behave badly, it is because they get something satisfying or rewarding from their bad behavior. Therefore to help children learn acceptable behavior, we need always to** CLEARLY LET THEM SEE THAT 'GOOD' BEHAVIOR IS MORE SATISFYING THAN BAD BEHAVIOR.

A BEHAVIORAL APPROACH TO LEARNING & IMPROVED BEHAVIOR

In this chapter, we explore ways to do this, using a 'behavioral approach' which you can divide into 6 steps:

1. Identify the behavior problems.
2. Carefully observe the circumstances of your child's unacceptable behavior.
3. Try to understand why your child behaves as he does.
4. Set a reasonable goal for improvement based on his immediate needs and his developmental level.
5. Plan to work toward the goal in small steps, always rewarding 'good' behavior and making sure 'bad' behavior brings no pleasure, attention, or reward.
6. After the child's behavior has improved, gradually move toward a more natural (less planned) way of relating to him.

Step 1. Identify the behavior problem.

A child may show many behavior problems. But if it occurs often enough then it is cause for concern. The first step towards behavior management hence includes listing of these problems in the child. Choose the problem behavior you want to change. Managing all problem behaviors at the same time may not be possible. So choose one or two of them to be managed at a time.

Step 2. Observe the circumstances of your child's behavior.

To help your child to behave more acceptably, start by carefully observing what is happening around and with the child when he begins his acts of disturbing behavior. **Observe carefully for a week or two.** To notice patterns more clearly, it helps **to write down your observations.** Try to **make your records clear, specific, and simple.** Take note of everything that might lead to your child's acts of 'bad' behavior, and **what he seems to gain from it.** For example, Rahul's mother might write these notes:



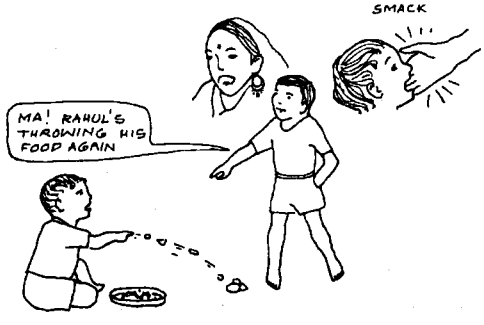
I put him in his chair, and gave him food.



"Then I got the older children ready for school."



"He kept calling to me, but I was busy and told him to keep quiet."



"Rahul began to throw his food ! I slapped him.



"He started crying. To quiet him, I fed him his breakfast."



"Then I put him down to play with his toys."

Step 3. Based on your observations, try to figure out why your child behaves as he does. Look for answers to these questions.

- What happens that leads to or 'triggers' this unacceptable behavior?
- **Why** did the child indulge in problem behavior? What exactly happened that lead to the problem behavior? Was the child refused something which he wanted or was he asked to do something?
- **When and where** does the problem behavior generally occur and with whom ? In the morning, at mealtimes, bed time,study time or when the child is sleepy, hungry etc. ? Does it occur at home, at school, in the market place or elsewhere ?
- **With whom** does the problem behavior generally occur more often? with parent, grand-parent, teacher or guest etc.
- Is his behavior partly due to **confused or unclear messages** from you or other persons? Does the child have difficulty in communicating to others, or that the task that you want him to do is too difficult for him.
- **What satisfying results does his behavior produce that might make him want to do it again?**
- **Is the child's behavior partly from feeling afraid or insecure?**

By repeatedly observing what happened before Rahul began to throw food, his mother started to find some answers.

- Rahul throws food most often when I leave him alone with it– especially when I am busy with the other children."
- "My own messages to Rahul are confusing and contradictory. At the same time that I scold him, I also give him the attention and care that he wants–like feeding him as if he were still a baby.
- By throwing food, Rahul gets a lot of satisfaction.

POSSIBLE EXPLANATION FOR RAHUL'S FOOD THROWING

TRIGGERS	WHAT HE LOSES BY THROWING FOOD	WHAT HE GETS
• Rahul is being ignored. He is left out while his mother is busy with the other children. • He may be afraid that if he feeds himself, he will be left out even more. He is very dependent on his mother's care and attention.	• His mother gets angry, slaps, and scolds him. 	• He gets the whole family's attention. • His mother quickly leaves the other children and goes to him. • If he cries when she slaps or scolds him, she quickly comforts him and cares for him like a baby. • And then he gets to play with his toys. • By being fed like a baby, he calms his fears of growing up and losing his mother's care and attention.

Understanding problem behavior is important for developing a management plan. Another simple **A B C** model is presented here which could be followed to understand and analyse why the child is indulging in a problem behavior and what benefits he is getting from it.

A stands for **Antecedents** which means observing the factors immediately before the problem behavior occurs. **B** stands for **Behavior** and **C** is for **Consequences** which means the factors that occur after the behavior.

Sonu's Crying and Screaming Behavior

A – Antecedents (before factors)	**B – Behavior** (crying &screaming)	**C – Consequences** (after factors)
Why: Whenever refused food or things she likes.	cries 5 to 6 times a day.	parents tell her to behave as per her age.
When: Any time during the day.	—	occasionally scold or hit her
Where In the shop and at home.	—	Father and brother generally give in to her the most.
With whom: parents and brother, more with the father	—	Mother gives in to her demands sometimes.

It is quite clear from the Sonu's example that when she is refused something she wants, she cries and screams and most of the time she gets what she wants. It also shows that parents are inconsistent in their handling. Giving in to demands no doubt quickly leads to stopping of the problem behavior, but only for the time being. In fact the chances are that the problem behavior becomes much more as the child generally gets what she wants.

Step 4 : Set a goal for improvement of the child's behavior based on his immediate needs and his developmental level.

If the child has several different behavioral problems, it is usually best to try to improve one at a time. Be positive. Try to **set the goal in terms of the good behavior that you want**, not just the bad behavior that you wish to end. For Rahul, the goal might be 'to learn to feed himself quietly (not simply 'to get him to stop throwing his food'.)

For example, thumb sucking in a one year or one and a half year old child is considered quite normal. But if this behavior continues it interferes with learning to speak. So it may become important to manage and correct this thumb sucking behavior.

Be sure that **goals are possible for the child at his developmental level.** (See p. 433). However behaviors can be targeted for management if they tend to interfere in the learning process, occur, too often or reduce social acceptability of the child.

Step 5. Plan a way to help the child improve his behavior.

Consistently reward 'good behavior. Each time the child behaves as you want, **immediately show your appreciation.** Rewards can be words of praise, a hug, a special privilege (perhaps the chance to play with a favorite toy. Or give the child a bit of his favorite food). However, food rewards should mostly be used only for very thin children or if nothing else works. **Avoid giving food as rewards to fat children** (see p. 416).

Building up good desirable behaviors is important. The skills that the child already has or the good behaviors that the child shows even though at low levels must be identified so that more good behaviors can be built on it.

Rewarding 'good' behavior **rather than punishing 'bad' behavior** brings improvement with much less bad feeling for both parent and child.

Always reward 'good' behavior and never reward 'bad' behavior. This is the key to the behavioral approach.

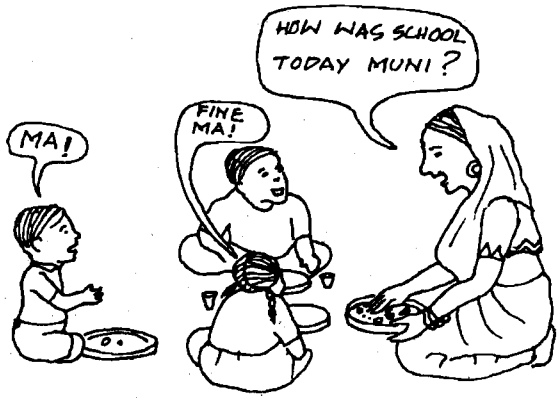
For example, whenever Rahul eats by himself, without throwing his food, the whole family can applaud and praise him.

Rahul finds that good behavior brings rewards and attention



But whenever he throws his food, the family ignores him, except perhaps to say "I'm sorry you did that, Rahul, "or, "Once more and I'll have to take your food away because I'm tired of having to clean up the mess. **Always do what you say you will do.**

He quickly learns that throwing his food now brings no reward.



How and when to reward

- Reward only good behavior and never any bad behavior.
- Reward immediately after the good behavior. The sooner the reward the better the effect.
- Be consistent in rewarding. Reward everytime good behavior occurs, specially when the child is being taught new behaviors. Once the behavior is learnt gradually reward the child for that particular behavior every now and then.
- Be clear in your tone of voice and expression while conveying your pleasure at the good behavior.
- Be true to your word. Do not promise anything to the child that you cannot give lest the child loses trust in you.
- Your reward should be proportionate to the behaviors. For example if the child's good behavior has lasted for a few minutes the praise should only be for a few seconds.

ADDITIONAL GUIDELINES

- **Be consistent** is how you respond to your child's behavior. If you sometimes reward good behavior and at other times you ignore it, or if you sometimes ignore bad behavior and at other times either scold or do what the child demands, this is confusing. His behavior is not likely to improve.

  WARNING: When using this approach, **at first the child may actually behave worse.**. When Rahul does not get his mother's attention by throwing his food, he may try throwing his bowl too. It is very important that his mother not give in to his demands, but rather be consistent with her approach. Only if she is consistent will he learn that he gets more of what he wants with 'good' behavior than with 'bad'.

- **Move towards training the child in skills little by little, in small steps**. If steps forward are small and clearly defined, often the child will learn more easily, and a beginning period of worse behavior can sometimes be avoided.
- If a certain behavior occurs in a child with a disability under certain circumstances, try and avoid those circumstances to prevent behavior problems.

For example, it would be too much to expect Rahul to suddenly eat by himself quietly when mother is busy with the other children. Instead, mother can help him work toward this goal little by little.

A possible first step is for Rahul's mother to give his food after the other children have left for school. This way she can stay close to him as he eats it.



The next step might be for mother to do her work while Rahul eats, but to keep talking with him and praising him when he does well.

In this way, Rahul will learn that eating by himself does not mean being left alone, but gets more attention from his mother than does throwing food.

Step 6. After the child's improved behavior has become a habit, gradually move toward a more natural way of relating to the child.

To help the child improve his behavior, the 'behavioral approach' just described often works well. Your responses to your child's acts are carefully planned and consistent. However, such a controlled approach to person–to–person relationships is not natural. Parents and children, like other people, need to learn to relate to each other, not according to a plan, or because each action earns a reward, but because they enjoy making each other happy.



Therefore, the last step, after the child's new behavior has been established, is to **gradually decrease immediate rewards while sharing the pleasure of an improved relationship.**

Kinds of benefits which children generally get by indulging in problem behavior.

1. **Social Attention** : A child may indulge in bad behavior if this will lead to attention from others– either verbal or physical contact from the the individual in the form of praise, a hug ,a nod or even eye contac. For some children negative attention may even maintain problem behavior; for example – scolding, commanding etc.

2. **Escape** : Many children indulge in problem behavior because it helps them to escape from demands, tasks or situations which they may not like.

3. **Self stimulation** : At times sensory and perceptual stimulations which one gets from indulging in problem behaviors makes one repeat such behavior. For example, a visually handicapped child may poke his eyes repeatedly because it may lead to flashes of light.

4. Children indulge in problem behaviors when they feel it will **get them something** for example, toys or clothes money etc. or will make it possible for them to do what they want to do like going out with friends, playing etc.

Setting reasonable goals – based on the child's developmental level

Be realistic when setting a goal for improvement in behavior, or a new skill that you want your child to learn. First try to determine the child's developmental level, and set a goal consistent with that level. (To determine the child's developmental level' see Chapter 35, "Child Development and Developmental Delay.")

Consider Sonu, the girl on p. 427 who has **tantrums** (crying and screaming fits) whenever her mother puts her down. Sonu is retarded, which means she is developmentally slow for her age. Depending on her developmental level (**not** her age), her mother can plan steps to help her avoid tantrums:

Suppose **Sonu is at the development level of a very young child.** She has poor hand control and no ability to play by herself, or to imitate (to copy) others. She will need to begin with very basic steps and clear, simple messages. Her mother can put her down briefly, then praise, talk, or sing to her as long as she does not have a tantrum. When she does have a tantrum, her mother should try to give her as little attention as possible and never give in to her demands. She can pay attention and reward her during those moments when she stops screaming–if only to catch her breath.

This way Sonu will begin to learn that she gets more of what she wants through good behavior than through tantrums.



Now suppose that **Sonu is at a more advanced level of development.** She likes using her hands and imitating her mother. Steps for improving her behavior can start from this level. Perhaps her mother can have Sonu sit at the river's edge and pretend to help her mother wash clothes. This way Sonu will feel closer to her mother and will be less afraid of being left alone. Her mother can talk to her and praise her all the time.



Note: At this level, Sonu will not be able to stay with one activity for very long. To avoid tantrums, her mother will need to keep the activities interesting by changing them often and talking to her a lot. In all of this, other children can be a big help.

Helping the child make sense of his world

The 'behavioral approach' to learning and development that we have discussed is similar to what is called 'behavior therapy' or 'behavior modification'. However, we prefer to put the emphasis on **improving communication** to help the child make sense of the world around him. Instead of our 'changing the child's behavior', we would rather **help the child to understand** things clearly enough so that he chooses to act in a way that will make life more pleasant for everyone. * To achieve this, **parents first learn to understand and change their own behavior in relating to their child. They look for ways to communicate with the child that are consistent and supportive, and that reinforce good behavior.**



A behavioral approach can often help **children who are mentally retarded or developmentally delayed,** such as Rahul and Sonu, to relate to other persons better and to learn basic skills more quickly.



Giving lots of attention, encouragement, and praise when he makes an effort is one of the best ways to help a child learn new skills. Photo : All India Institute of Medical Sciences, New Delhi.

This approach can be used at almost any age. It is often easier with younger children (developmental age from 1 to 4). Starting at a young age can prevent small behavioral difficulties from becoming big problems later. For the very young or severely retarded child, goals must be kept basic and progress toward the goals must be divided into small steps. To master each step, **much repetition may be needed** with consistent praise and rewards for each small advance.

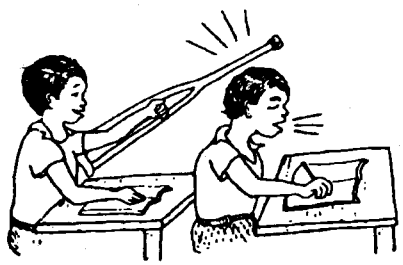
Mentally normal children with physical disabilities sometimes also develop unacceptable patterns of behavior. A behavioral approach may help them also. The story on the next page tells how this approach helped George, from p.427, to behave better.

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*This is the point of view in Newson and Hipgrave's *Getting Through to Your Handicapped Child*, from which many ideas in this chapter are taken, and which we strongly recommend (see p. 773).

THE STORY OF GEORGE

George is an intelligent 10 year old whose legs are paralyzed by polio. He lives with his grandmother. He is noisy, rude, bad tempered, and whenever he plays with other children, it turns into a fight. George has caused so much trouble in the classroom that his teacher recently told his grandmother he will throw George out of school if he does not change. Both his teacher and grandmother have tried scolding him and whipping him, but it only seems to make George's behavior worse. As his grandmother says, "He loves to make people angry at him".



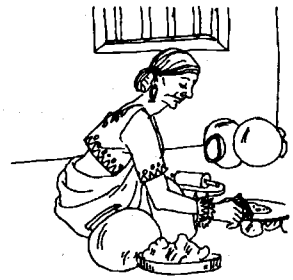
Not long ago, George's grandmother took him to the village rehabilitation center to ask for advice. A village worker helped her to observe both George's and her own behavior more closely to better understand why George acts the way he does. She realized:

- When George is quiet, and well-behaved (which is not often), everyone ignores or forgets him.
- As a result, George feels unwanted, unloved, and useless. Starved for emotional human contact, he gets it by making people angry with him.
- George's bad behavior, therefore, brings him a lot of person-to-person contact, even though it is painful. The few times he tries to be good, he is made to feel unwanted and unneeded.

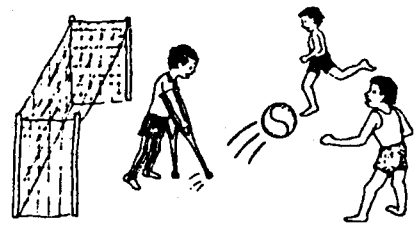
"I really do love him," said his grandmother. "But I guess I don't show it much. He makes me worry so much!"

To begin to behave better, George needed to find out that friendly and helpful behavior can bring him closer to people than bad behavior. For this reason, the village worker-together with the grandmother, the schoolteacher, the school children, the rehabilitation team, and George himself-helped figure out ways that would let the boy see that 'good' behavior is better than 'bad' behavior.

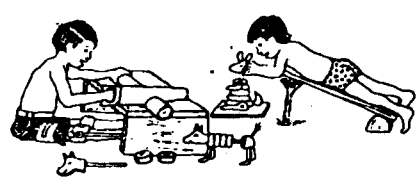
At home, grandma began to look for things George could do to help her, and to show him how happy she was when he did them. She made a backpack, open at the sides, so that he could help bring firewood. Also, she learned to quietly turn her back when he misbehaved, and to let him know how happy she was when he would sit quietly doing his homework or shelling the maize.



At school, the teacher discussed with the other children ways to include George in their games. When they all played football (soccer), they let him be 'goalie'. To everyone's surprise, George was an excellent goalie. With his crutches he could reach farther and hit the ball farther than anyone else. Soon all the children wanted George to play on 'their team'. At first George started a few fights. But when he did, he was quietly asked to sit on the sideline. Soon he learned to stop hitting other children so that he could keep hitting the ball.



In the village rehabilitation center the village worker invited George to help make educational toys for young and disabled children. He helped George get started and praised him for each toy George completed. Soon George learned to make the toys by himself and took great pride in his work. When he saw other disabled children playing and learning things with his toys, it made him very happy. He decided he wants to be a rehabilitation worker when he grows up.



Ways to avoid behavior problems.

There are no ready made recipes for management of behavior problems. A number of methods have been used successfully.

1. **Changing the factors that lead to problem behavior**

For example when Lalita is feeling sleepy and her mother asks her to study, she refuses to do so. This happens every time she has to study till it becomes a behavior problem. Her mother then decides to change her study time. So instead of forcing Lalita to study when she is sleepy, her mother makes her do so when she is more active. This and other similar problems can be corrected by changing the factors that lead to problem behavior.

- At times asking the child to do certain tasks which are difficult for her may lead to such behavior. So avoid asking the child to do such things that he is incapable of doing.
- Many children do not like sudden changes. So to prevent bad behavior they need to be prepared for the change.
- Provide environments to involve them in stimulating activities to help them learn and behave better.

If you are able to find out that the bad behavior brings social attention, then the best method to manage that problem behavior is to **ignore** it. In other words pretend that nothing has happened and continue to do your work as usual and pay no attention to him. **Ignore only those behaviors that are not harmful to the child and to others,** for example, crying, screaming and shouting or asking the same question repeatedly.

Remember

- Praise the child when his behavior is good.
- While using the method of ignoring, problem behavior may seem as if it is getting more before it starts to lessen.
- Once the problem behavior to be ignored is decided upon, all persons involved in the process of management should agree to do the same.

2.'Time Out' or 'non–reward' instead of punishment

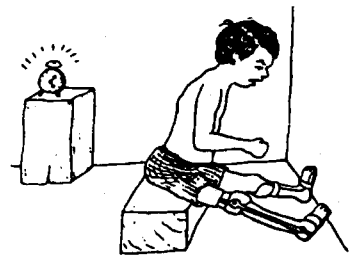
The story of the way family and friends used the 'behavior approach' to help George sounds fairly straightforward and simple. But in real life it is seldom that easy. 'Bad behavior may sometimes be so bad that it cannot be ignored.

In general, the best way to make 'bad' behavior seem boring to the child and not worth the trouble is to give no rewarding response. At the same time, make sure to reward 'good behavior. This means everything satisfying stops as a result of 'bad' behavior (instead of the usual situation where everything satisfying starts).

For example when Rahul throws his food, instead of entertaining him by scolding and feeding him, his mother should remove both the food and herself for 3 or 4 minutes making the situation as boring as possible.

Removing food may seem like punishment. But it is best to aim at **making the situation less interesting** rather than making it unpleasant. To make things less interesting, sometimes we may remove the child from the situation for a brief time. This is often called **'time out'**

For example, when George's grandmother first began using the behavioral approach, to try to make her angry he would shout and hit the chickens with his crutches. But instead of her usual scolding, grandma now simply told him that if he did not quiet down she would ask him to take 'time–out' in the corner. Then, if he continued to make trouble, she would lead him to the corner and tell him that he would have to stay there for 5 minutes from the time he was quiet. She set an old alarm clock to ring in 5 minutes. At first George would continue to shout from the corner, but each time he did, grandma would set the alarm to ring in another 5 minutes from the time he was quiet. Meanwhile she gave him no attention and continued her work.



In this way, George learned while he was in the corner that the only way to make life interesting again was to stop making a disturbance. Because he was clever, he learned fast. (Slower children often take longer).

We should try to use 'time out' as a 'non–reward' and not a punishment. However, because time out is something an adult makes a child do, it can seem like punishment. Try to use it only when less forceful methods of avoiding rewards do not work. It is best to start with a 'time out' period of no more than 5 minutes (less for a very young child). If the child does not behave better in 5 minutes, consider with the child adding another 5 minutes. **Never leave the child in ';time–out' for more than half an hour,** even if he has still not become quiet.

REMEMBER

- The room in which the child is separated should be a boring place. (bathrooms, bedrooms etc are sometimes very enjoyable for children).
- You should make sure that the child cannot lock himself from the inside.
- The room should be safe from sharp things or electric points etc. with which the child may hurt himself.
- Be consistent in the use of Time Out that is applied every time the child repeats the problem behavior.
- Time Out teaches the child what not to do. It is important to give rewards to the child for good alternate behaviors.

Time out can be used generally with aggressive, destructive behaviors. For example– hitting others, throwing or breaking things etc. Avoid using Time out for problem behavior which are self injurious to the child.

CAUTION: Try to avoid using time out for children who have fits self injuries behavior on those who like to be left alone and indulge in repetative behavior like rocking etc.

3. Verbal disproval

It is important to convey to the child in a clear and emphatic way that his behavior is not liked by others.

4. Mild physical restraint

Holding a child's hands firmly behind him for 30 seconds to 2 minutes saying loudly, "Stop it" does sometimes help to control the problem. Many behaviors such as hitting others, throwing things, picking at wounds, slapping or hitting oneself or others, thumbsucking etc. can be managed by this technique. If problem behavior increases it is probably because of the attention the child is receiving. In such a case choose another method.

5. Restitution (Return to former situation)

This method can be generally used for children who can follow simple instructions and are able to physically do the task asked for. Behaviors such as throwing food, clothes or books around, leaving the play area in a mess etc. If verbal instructions are not obeyed, then the child's hands should be physically guided to complete the work. The child need not be rewarded for the work done.

A BEHAVIORAL APPROACH TO CHILD DEVELOPMENT AND LEARNING NEW SKILLS

In this chapter we have talked mainly about correcting 'bad' behavior. However, the behavioral approach can also be used to help children learn basic skills for their continuing development. The approach is often useful for children who are slow to develop–for either mental or physical reasons.

In Chapter 35 on child development, we introduced the key features of a behavioral approach: (1) make messages clear, (2) consistently reward things learned and (3) advance toward new skills through small steps. You will also recognize this behavioral approach in the chapters on 'feeding', 'dressing', and 'toilet training'. Here we would like to review ways of applying a behavioral approach to a child's basic development and learning.

Looking at the whole child to decide where to begin

In considering how to help a child's development, start by looking at what the child can and cannot do. In terms of behavior, we can group our observations into 4 sections.







- **Positive behaviors**: skills and characteristics the child now has–particularly those that may help him in learning something new. (For example, he enjoys being praised).
- **Negative behaviors**: Things he does that are dangerous, disturbing, or prevent his progress. For example, breaking things, hitting people, screaming when bathed, throwing toys rather than playing with them).
- **In between behaviors**: These have both positive and negative aspects, and need to be worked with to make them more positive. (For example, for a child who is beginning to feed herself, but who smears food all over; we encourage feeding herself (which is positive) but not smearing (which is negative).
- Even screaming or crying in order to express a need might be considered positive for a child who has great trouble communicating. We need to help this become more satisfactory communication.)



- **Key needs**: These are problems in the child's behavior that need to be solved to make progress with learning. They differ depending on the stage of development. (For example, for a child to learn from his mother, he needs to respond to his own name, to look at her when she speaks to him, and to stay still and give attention for at least a few seconds. These 'key needs' suggest the first steps in learning to speak, play, or develop new skills).

It may help to write a list of these different behaviors. Here is a list that a little girl's mother made with the help of a village health worker who studied this book.

Child:
Meena

Age 4



POSITIVE BEHAVIORS –ones she now has that we can build on	IN-BETWEEN BEHAVIORS– ones that have both good and bad points	NEGATIVE BEHAVIORS– ones that prevent her progress or disturb the family
• smiles when praised  • can feed herself with her fingers • can put 3 rings on a peg • undresses herself • enjoys rough play • enjoys being bathed • says 6 words: mama, dada, bottle, sweets, pee-pee and NO!	• plays only a moment with toys–then throws them. • says 'pee-pee then wets her panties`  • **will not sit still** for a minute– except for food.	• kicks people when she gets upset. • carries around a baby bottle all the time, and screams when it is taken away. • spits her food at others 

KEY NEEDS (in order that new skills and behavior can develop)

- sitting down and giving attention for a longer time.
- getting rid of the baby bottle to free hands for other things

Deciding where to begin

After they listed these behaviors and considered Meena's key needs, the health worker helped her mother plan where to begin. He explained that, since **we cannot change everything at the same time,** we need **to decide what things need to be done first** (choose priorities for action). So we choose the behavior we most want to introduce or change.

- If we are trying **to introduce a new behavior or skill,** we need to think of all the **different parts** that make up the behavior. Next we plan the separate **small steps** that lead to the skill. We encourage the child to advance step by step, making clear what we expect for each step and consistently giving **praise and small rewards.**

- **To improve an 'in–between behavior',** we can help the child by working with a skill she has already developed a little. First we need to think about the various **parts of her behavior** that concern us. Then we decide **which parts seem helpful and which do not.** We then **reward the good behavior and ignore the bad.** As the child gradually improves, we can expect more of her before giving a reward, until the whole improved behavior is achieved.

- If we are trying **to reduce or stop an old behavior** we need to do 2 things. First we note **when** and **where** the behavior happens, and **what happens before, during, and afterward.** We observe carefully **both what the child does and what we ourselves do.** Second, we try to guess what the child gains from her 'bad' behavior. We can then try to **change things so that good behavior is more worthwhile than the 'bad'.** To do this we **reward the new 'good' behavior and refuse to give attention for her 'bad' behavior**

Thinking about Meena's behavior, her mother realized that she already has the beginnings of **many valuable skills.** She uses her hands well and has begun to develop skills for **feeding** and **dressing** herself. She also **speaks a few words**– although it would be nice if she could say 'yes' as well as "no".

It is important that she **likes praise** and hugs, and bathing, and rough play. This means she will probably learn well with a reward–based approach.





However, **certain things seem to be stopping** Meena from developing her skills more. Not being able to sit and give attention makes it hard for her to learn from other people, or even to learn to enjoy her toys (which she always throws). Also, her **baby bottle is a big problem.** She is much too old for it, but her mother is afraid to take it away because Meena screams. Her mother fills the bottle with sweet drinks (which have already begun to rot Meena's teeth) The biggest problem is that by always holding her bottle, Meena's hands are not free to do other things–such as play with her toys or take down her panties when she has to pee-pee.

For these reasons, Meena's mother decided that the 'key needs', which need to be solved in order to advance in other areas, are:

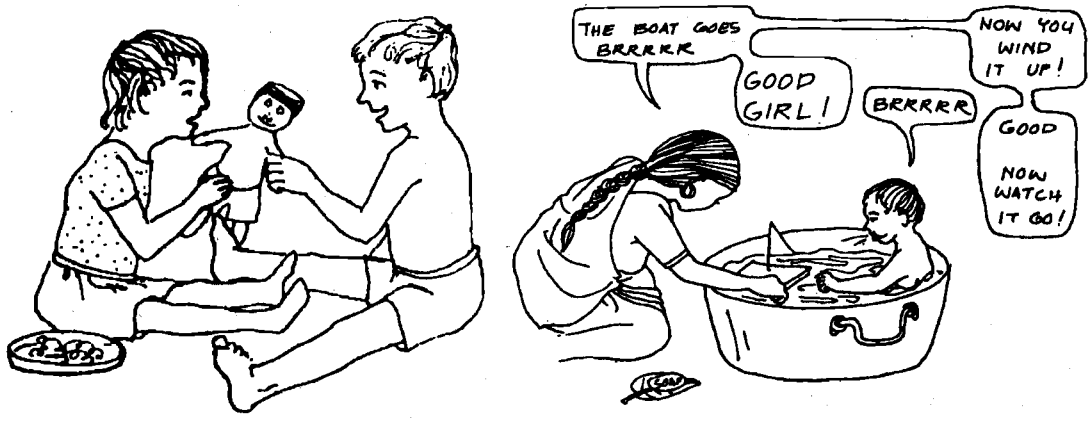
- **helping Meena learn to sit quietly and give her attention to something**

- **helping Meena grow out of her need to always hold her bottle.**

The health worker discussed with Meena's mother what she might do. To help Meena learn to sit quietly and pay more attention to things, her mother decided to start with the times when Meena was already willing to sit fairly quietly–which was mealtime and bathtime. For example:

After giving Meena her food, but before her final sweet, her mother or her older brother, Oscar, plays quietly with her for 5 minutes or so, praising her whenever she gives attention.

Her mother also uses bathtime as an opportunity to help her concentrate on toys and to give attention to words and sounds.



Meena's mother decided to help her outgrow the bottle little by little. For a start, she filled it with water only. After a few days, she refused to fill it at all.

At first Meena screamed and kicked. But her mother did her best not to give Meena any attention when she acted that way. As soon as Meena was quiet, however, she would give her a tasty drink from a glass, or some other reward.

Sometimes Meena would throw her empty bottle in anger. But after a while she began putting it down, more and more often, to pick up other toys or objects. Finally, her mother simply removed the bottle from sight.



After Meena had forgotten her bottle, she started to explore more with her hands. When she needed to go 'pee-pee', she began to lower her panties by herself; in a few weeks she was 'toilet–trained'. She also began to play with her toys more, instead of just throwing them. As she learned to give longer attention to things, she discovered lots of things that gave her pleasure. Many of her behavior problems such as screaming, spitting food, and kicking began to disappear. Her mother, father,and brother spent more time playing and talking with her. They praised her when she behaved well, and did their best to ignore her 'bad' behavior.



Where it seemed necessary, her mother began to use a behavioral approach to help Meena develop other skills; dressing, eating, and talking. To increase her language skills, together they looked at picture books and listened to songs.

As a result of her family's efforts, Meena has grown up a lot, and is a much happier and more able little girl. Thinking about the changes that took place, her mother said, "I think my behavior has changed as much as Meena's. I was still treating her like a baby–bottle and all! Now that I expect more from her and show her how much I appreciate her effort, she has developed a lot faster, and is a lot easier to live with. She and I have both come a long way!".

Examples or methods for helping children develop basic skills using a behavioral approach are discussed in other chapters: Feeding, Chapter 37; Dressing, Chapter 38; and Toilet Training, Chapter 39. We suggest you also read again the chapter on child development, Chapter 35, and consider how a behavioral approach can be useful for helping a child through many difficult areas of development.

PARTICULAR BEHAVIOR PROBLEMS THAT OCCUR IN SOME DISABLED CHILDREN

Disobedience is one of the most common complaints that Indian parents have. Disobedience can mean many things from not doing what the child is asked to do or taking too long to do it, to doing the exact opposite of what he is asked.

Many children with a disability are unable to carry out the commands because of their inability to follow instructions. This then cannot be called disobedience.

What do you do when your child is disobedient ?

When parents are inconsistent in handling their child then they go wrong. For example Nitu's mother tells her to gather her toys that are scattered around and put them in a box. Nitu turns a deaf ear and continues to talk to her brother. Despite her mother repeating the instruction several times Nitu does not obey. Her mother then scolds her, then gives her a slap. There is still no response. Finally Nitu's mother picks up the toys and puts them away in the box.

This kind of management encourages the child to continue with the problem behavior because she is allowed to get away with it. This inconsistency also leaves the child confused.

What to do when your child is disobedient ?

1. Give clear, specific and brief instructions in a normal tone without commanding.
2. When verbal instructions are given to the child and the child does not obey, repeat the instructions only once more unless the child is mentally retarded or hearing impaired.
3. Wait until the specified time limit you have set for the child to do the task.
4. Do not argue with the child or raise your voice.
5. If the work has not been done during the specified time make him carry out the instruction. If the child resists then physically guide his hand to do the work.
6. Never allow the child to escape from doing the task assigned.
7. Do not reward the child or promise to give him things while the child is resisting to carry out the instruction.

Discplining all children is important. Even more necessary if they are disabled as their training occurs under more controlled situations where discipline or following instructions becomes a prerequisite.

HYPERACTIVE CHILDREN

Hyperactive children show the following tendencies which are often difficult to control. These children show a restlessness – constantly moving around, unable to concentrate or finish tasks given to them and often become disobedient.

In dealing with hyperactive children you need to ask yourself several questions.

- Do you generally allow him to leave work and roam around ?
- Do you constantly repeat instructions or keep shouting at him?
- Do you hit him at times to make him sit and work ?
- Does the child find the task you have given him interesting? Is the task too difficult or too easy for him to do?
- Is it that you ignore him when he is actually sitting and doing the task?

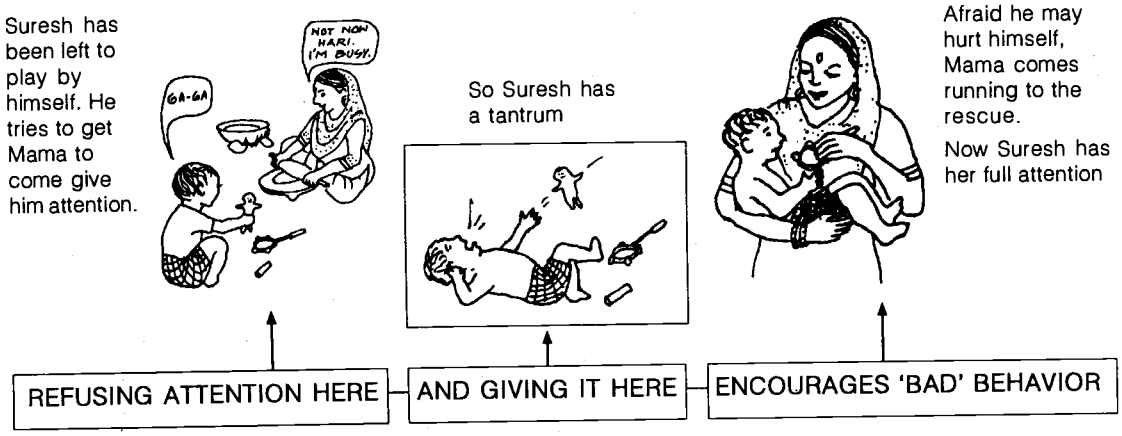
Answering these questions will perhaps help you understand the reasons for overactivity or inattentiveness in your child.

Tantrums

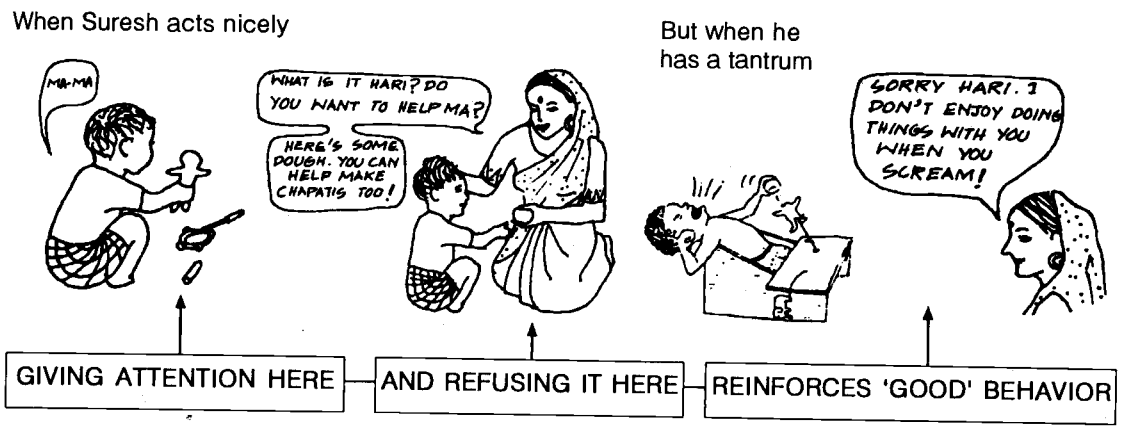
"Tantrums' are fits of crying, screaming, and angry or destructive behavior. The child may try to break, throw, kick, bite, or in other ways damage anything or anyone within reach– sometimes including himself.

Tantrums can be frightening, both to the child and the family. after a tantrum begins, it is difficult to 'reason' with the child and calm him. Punishment often makes it worse.

Children– including some retarded and physically disabled children–may learn to use tantrums to get what they want. Sonu, on p. 434, is one example. Here is another:



In this way children discover that tantrums get them what they want. To help a child having fewer tantrums, parents need to help the child find other, more acceptable ways of showing his wants and fears. And most important, parents need to **reward the acceptable ways**, and at the same time **refuse to give the child attention** when he is having a tantrum. Let's look at how Suresh's mother learned to do this.



Thus, by rewarding Suresh's good behavior and by refusing to give attention to his demands when he does have tantrums. Suresh's mama helped him learn that **tantrums do not get him what he wants**. At first he had more violent tantrums than ever. But when even these failed to give exciting results, little by little he stopped having tantrums. He found that other forms of communication gave more satisfying results.

Holding breath



"Not giving attention during a tantrum sounds very nice. But my child **gets so angry, he stops breathing and turns blue!** I can't just do nothing!

But doing nothing is often the best way to prevent your child from holding his breath more often!

The **child will not hurt himself by holding his breath**. At worst, he will lose consciousness and begin to breathe normally, long before the lack of air causes any damage.

Once a child learns that holding her breath frightens and confuses her parents, she is likely to repeat it every time she gets angry at them. (Many completely normal children do this). We need to try **not** to show worry or concern when the child holds her breath and turns blue. Instead, we should wait until she gives up trying to frighten us and begins to breathe normally again. Then we can do something to show her how much we love her. But **not** while she is holding her breath!

Head banging, biting, and other self-damage



Children may do these things for the same reason they hold their breath–to frighten and punish their parents.

Sometimes however, children with brain damage, epilepsy or severe mental problems may form habits of biting themselves, banging their heads, pulling out their hair or other self-destructive behavior.



To stop a child who is hurting himself, hold him from behind tightly, but quietly, so that he does not see you and gets as little response from you as possible.

Whatever the cause, acts of self-destruction cannot be ignored. Parents should look for the most simple and calm way possible to gently stop the child from injuring herself. For example, they can hold the child's arms to keep her from biting herself.

However, often a behavioral approach helps solve these problems. Take care **not to get excited or give the child extra attention** when she hurts herself. At the same time, make every effort to reward positive behavior and to help the child gain self–confidence, learn new skills, play with toys and other children, and have friendly interaction with other people. Of course, some children's mental ability will not allow much learning or play.

Showing these children a lot of affection, hugging them, talking and singing to them, and doing things with them that they like, **at times when they are not harming themselves** may help them to stop such acts. **Rewarding a child wwhen she stops a self–destructive act** may help a child to not act that way so often. But be sure to reward and give the child even more attention at times she has not been harming herself. When possible, get advice from a child psychologist.



STRANGE BEHAVIOR

Children with different disabilities sometimes develop unusual habits or patterns of behavior. This is especially true for retarded or brain–damaged children who may be confused or frightened because they have difficulty understanding what goes on around them.

In helping children through such difficulties, first try to understand what might 'trigger' or be the cause of the behavior. For example:

Rocking



"John often starts rocking back and forth, and seems to escape into his own world! He then shows no interest in anything that is happening around him. Sometimes he rocks for almost an hour."

"When does this happen most?"

"Mainly when he is with a group of other children, or when there are guests. But sometimes when he is just alone.".

John seems to withdraw into his world of rocking when things get too confusing, frightening, or even boring, for him. To stop rocking he may need to be helped, little by little, to discover that interaction and play with other persons and things can be enjoyable. But to avoid confusing and frustrating him, new people, toys, and activities will need to be introduced gently, a little at a time, by the persons he knows and trusts most. You might praise or reward him when he smiles or shows any interest in playing with other children, or with new toys. When he starts to rock, try to interest him in things you know he likes. (But make sure to spend **more time doing things he likes with him when he is not rocking.** Otherwise you will be encouraging him to rock more often to get your attention).

Eye–poking



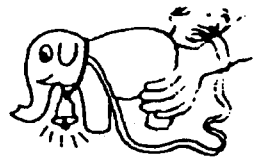
"My 5–year old daughter, Judy, is blind and somewhat retarded. She has a habit of poking her fingers deep into her eyes. As a result, her eyes often get infected.".

For Judy, who lives in the dark, life is not always very interesting. She cannot see things to play with. When she tries to explore, she bumps into things. She has found that poking her eyes causes flashes of light, so she has made a game of this. Also,

she has discovered that when she pokes her eyes her mother comes running. Sometimes mother slaps her hands, but at least she gets attention!

For Judy to learn not to poke her eyes, she will need a lot of help to find things to do that are more interesting and rewarding:

- toys that have interesting shapes and surfaces and that make different sounds.
- perhaps her own 'space' or part of the house where everything is always kept in the same place so she can learn her way around and find her toys (See Chapter 30 on blindness).
- giving her more attention and praise when she does not rub her eyes than when she does.



Whenever your child develops behavior that you have trouble understanding, it may help to ask: **What does the child gain from the behavior? What are his alternatives and in what way do they offer him less reward?** And, **how can we help provide alternatives that are more rewarding to him?**

CHILD GUIDANCE SERVICES

There are many reasons why childern have behavior problems. It may result when basic needs are not met, as it may happen when one or both parents may not be alive, quarrels or separation of parents, being ignored by parents, trying to meet their high expectation, some traumatic experience or poverty.

With increasing population and migration of people into towns and cities, the growing up years are becoming very difficult for children, even more so for children with disabilities. The joint family is giving away to nuclear units, and in an extremely competitive and acquisitive society, the children face stresses and strains and are loosing emotional and social security. Because they are unable to cope with these pressures more and more children are showing a wide range of problems, such as learning disabilities, lack of attention, truancy, problem relating to eating, sleeping, toilet and speech. Many children are unable to adjust with other children at home and in school. Thus growth and development of a child is sometimes hampered and the child is unable to reach her/his full potential.

Such problems are very different from physical illness or disability and cannot be tackled by doctors, because they are not necessarily medical problems. To get help in managing behavior problems of children, the Child Guidance Services were started. They are located mainly in the psychiatry (mental health) and paediatric (children) departments of hospitals, social work departments of universities and colleges of nursing. Such services are also offered in schools providing special education to disabled children and child welfare organisations of the government and non-government. Child Guidance Services meet these special needs of children with behavior problems. These centres are mainly located in the urban areas.

How does a Child Guidance Centre function

The main function of the CGCs is to understand problem behaviors, the reasons for such behaviors and offer guidance to parents for their management.

These centres offer guidance, counselling and therapy according to the needs of the child. The child guidance team consists of a psychiatrist, a clinical psychologist and a social worker. At first the social worker collects detailed information. The psychologist then

checks the child for his social, emotional and intellectual level and for any other particular problem that the child may have. The psychiatrist examines the child for possible brain damage or any other cause of the problem. A large number of children with mental retardation are referred to the CGC.

The treatment or therapy then provided is need based and may include the following:

1. medicines/drugs
2. speech therapy
3. guidance and counselling
4. play therapy
5. behavior modification
6. educational level so that an educational plan prepared specially for the child.

For any other specialised treatment the child may need, he is referred to the concerned hospital or agency.

The child guidance centres also offer guidance and advice to the parents about their own behavior towards the child.

There are about 100 child guidance centres functioning in the country. The structure and functions of these centres varies depending on where they are located. Some of these centres are attached to the paediatric (children) and psychiatric (mental health) departments of hospitals. Others are in academic institutions.

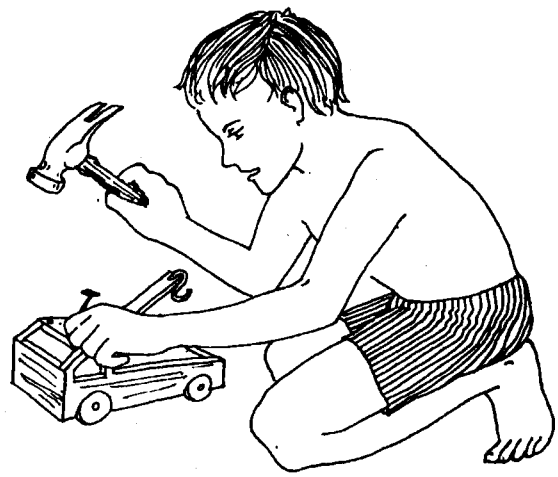
A list of child guidance centres in India is given on page. If you are in need of these services, ask your health or rehabilitation worker for help to reach the nearest child guidance centre.

CHAPTER 42

'Learning Disabilities' in Children with Normal Intelligence

Some children, who in most ways seem normal, have difficulty learning or remembering certain things. They may be able to perform most activities of daily living but have difficulties with regard to their educational performance. Some of these problems include:

- problems in copying and writing
- problems in listening or understanding
- difficulty with numbers
- poor speech in some cases.



The child who has difficulty learning or remembering certain things may show unusual skills or talents in other ways. In some ways, he may prove to be more intelligent than average.

These **blocks** to learning may happen in a child who is as intelligent or even more intelligent than most children of the same age. Generally these children also have normal vision, hearing and normal limbs without any deformities. They also have adequate opportunities for learning. There is no brain damage, and no lack of environmental or emotional support. Their difficulty in learning therefore is due to the processing problem. It is because of assumed neurological dysfunction that children have problems in learning.

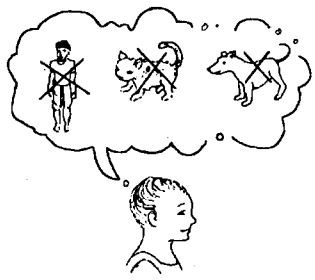
Learning a concept: we go through several stages before we learn something. This is called the learning process.

Let us see how this happens with the following example of a COW.

We first receive the information through one of the five senses– VISION, HEARING, TOUCH, TASTE and SMELL.



1. When we look at a **COW** for the first time, the sensation is carried through the eye to the brain.



2. We see it as something that is different from dog or cat or human being. With this knowledge we have learnt the ability to discriminate.



3. The next time we see a cow we remember.



4. When the picture of a cow isshown; the name is written and shown or the name is spoken, it is associated to the object and stored in the mind.

5. Thereupon, everytime the word COW is spoken, shown or written, it is associated with the real cow.

Thus if the child is able to recall the word 'COW' when he sees the picture of a cow, hears its name, or sees a real cow, then he has learnt the concept and is able to apply it.

When we say that we have learnt something, the learning would have gone through all these steps. Learning disabled child has a **'block'** or breakdown in one of these steps and that is why the child is unable to learn a particular concept.

Such problems as mentioned earlier may be specifically in READING, LISTENING, SPELLING and ARITHMETIC. DYSLEXIA is the term used for reading disorders. Earlier learning disorders were identified with this. But now Dyslexia has become part of a much broader term LEARNING DISABILITIES which include a wide range of learning problems. These children have difficulty concentrating, have poor memory, they omit, add or substitute letters or words while reading or writing. They may reverse letters or words, may not maintain 'left to right'orientation while writing and get distracted easily. However the combination of difficulties varies from child to child. The child may display one or more of these signs.

Any child who in the first years of life seems to develop abilities and understanding about as quickly as other children, yet at a certain age begins to show difficulty in learning or remembering certain things, may have this kind of special learning disability. Usually these children are blamed for being clumsy or lazy and may have behavior problems. In some countries they have remedial educational facilities in schools for normal children. In many countries however they continue to attend regular classes without benefitting much from the education they receive. Finally they drop out of school or learn some vocational skill by themselves or through someone who has identified the strengths of the child rather than blame his weaknesses.

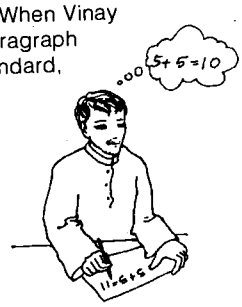
In developed countries at least one child in 30 is thought to have a learning disability. In developing countries like India however such children are not so easily identified, specially when the literacy rate is low even among normal people.

VINAY

Vinay was very poor at his studies. His father complained that he could not even read simple sentences or do simple sums of two digit additions or subtraction. While taking dictation he would make errors even with four letter words.

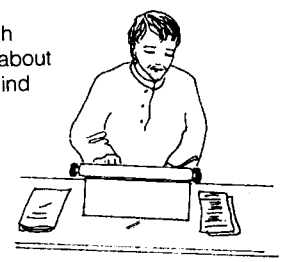
Seventeen year old Vinay belongs to an urban family concerned about his future. What could he do without even a basic education? This was the question his parents asked.

Vinay's parents were told that their son needed help and they sought it. When Vinay was asked to read a paragraph from a book of the II standard, he traced the lines with his fingers, spelt out the letters and then tried to blend the letters into a word. But when a paragraph was read out to him, he could comprehend the message. When he was given dictation he either left out letters or jumbled them up while writing a word. For instance for the word STOP he wrote SPOT.



Except for his academic backwardness, Vinay was behaving in a manner appropriate for his age in all other aspects. It was also noticed that he had an aptitude for drawing and painting.

Vinay was provided with remedial education for about two years keeping in mind his strengths and drawbacks. To correct his problem in visual processing of information, he was sent to a typing school after explaining his problem to the teacher. Simultaneously for his reading, writing and arithmetic, he was given remedial education and also special preparations were made so that he may get admission to an art school.



Now Vinay has been able to overcome many of his problems. He can type sentences though not with the required speed and he makes very few mistakes.

He can read books of the fourth standard and can also read the headlines and simple news items in the newspapers fluently, without using his fingers to trace the words.

In arithmetic too he has learnt, not only addition and subtraction but also multiplication and division. He prefers to do them mentally rather than use a paper and pencil. He tends to make errors with paper and pencil. This again can be attributed to his problem of reading disability.

Vinay is now a confident young man wanting to study arts and looking forward to a good future.

HOW TO IDENTIFY

Observe the child carefully and look for some of these signs that suggest problems in Reading, Wrting, Mathematics and General behavior.

Look for these signs

READING

- Omits, adds, substitutes, reverses letters in words.
- Skips lines or words while reading.
- Does not recognize a whole object when only part of it is shown.
- Unable to focus on specific word or figure on a crowded blackboard or printed book.
- Does not blend letters into a word – says 'b–a–t–' but does not blend as 'bat'. But if the word 'bat' is spoken, or read, the child can say it.
- Has problems in following verbal instructions without accompanying gestures.

MATHEMATICS

- Confused with terms 'more– less, 'after– before', 'yesterday, today, tomorrow', '30 minutes– 2 hours'.
- Says multiplication tables but cannot use them meaningfully.
- Identifies numbers in sequence but cannot when singled out.
- Reverses numbers– 6 for 9, 36 for 63, 14 for 41 and so on.
- Can compute addition/ subtraction on paper but cannot relate to a living situation as in a shop.
- Gets confused with mathematical signs– >< – + ...
- Does not seem to understand 'carry over ' in addition and 'borrowing' in subtraction.

WRITING

- Does not maintain left to right orientation.
- Clumsy and illegible handwriting.
- No spacing between words.
- Disregards lines in paper while writing.
- Cannot take dictation if there is an outside noise (that means he cannot differentiate between the focus and background sound).
- Reverses letters or words (mirror writing)
- Omits, adds , substitutes letters in words.
- Does not maintain columns and rows in arithmetic.
- Can copy correctly but makes mistakes in dictation.
- Can answer questions correctly but cannot write.

GENERAL BEHAVIOR

- Tends to be on the move most of the time.
- Cannot sit or stand still.
- Disorganised with his personal belongings such as school bag, lunch box, water bottle, clothes, shoes / slippers etc.
- Appears to be "moody".
- Gets easily distracted.
- Appears to be forgetful, but seems to remember events occured long ago.
- Seems to have problems in shifting from one activity to another.

CAUTION: The problems as mentioned above may be in various combinations and it is also not necessary that all symptoms must be present. Any one of these signs present need not necessarily mean that the child has a learning disability. There may be several reasons for his inability to learn. There may be additional problems. It is possible that the child is unable to learn because he has hearing difficulty, is a slow learner or is hyperactive. Therefore before concluding that a child has a learning disability it is important to look all the different aspects of development in the child.

When most of these symptoms are present in the child, then he requires assistance in education. In most cases appropriate education will correct the problem. If it is not possible they can be compensated for.

For example:

1. A child's illegible writing may also be because he has difficulty in hand movements.
2. Reversal of letters as in **p** and **q** or **b** and **d** may be done by any child. It may become a sign for concern only when the child continues to do this even after the age of 7 years.

WHAT TO DO

- These children (even more than most) have a great need for love, understanding and appreciation of the things they do well.
- It is very important not to call these children stupid or idiots. As they will already be aware of their problem, such comments would further create psychological problems in them.
- Highlight their brighter aspects and strengthen their abilities.
- Often the best way to help a child learn in the area she has problems in is to try to teach with concrete examples, gradually moving to abstractions. This way they learn and relate better. Use activities the child likes and can do well.

  For example: A child who has difficulty learning and using numbers, but likes building things, can gradually begin to take measurements for cutting and shaping the pieces for the things he builds.



- Multisensorial approach in teaching is often beneficial to them.
- Do not blame, scold or punish the child for not learning, or for 'not trying'. This may only make things worse. A child can easily become frustrated with her special learning difficulty. Trying to force or shame her into learning can make her more restless, angry or rebellious. Some children will not admit to themselves and to others that they have trouble learning something. Instead they hide their

difficulty by pretending that they do not want to learn. Thus a child who has a special learning disability may be mistaken for one who is simply stubborn, lazy or a trouble–maker. The child may become defensive and uncooperative. You will need to show a lot of understanding, patience and proof of your respect for the child in order to win his trust and cooperation. But after trust and respect are established, he may become as eager and considerate as he was stubborn and troublesome before.

- Special help with learning may be needed. It often works best to move forward in small steps, with much repetition, so that the child finds it easier and gains confidence. (see chapter 35). Make study periods short and mix them with activities that the child likes. And ofcourse, try to make learning fun.

- Let the child learn and use what she learns, at her own speed. Do not hurry her. Help her relax. It has been found that when children who have difficulty with reading or writing are given all the time they need to take tests, they often do as well as other students.

- Some very intelligent children never learn to read or write. Some of these children, if given a chance to study with the help of tape recorders or other means, have completed university degrees. Others have preferred to leave school and learn other skills. Many have become leaders in their communities or work places. What is important is to help and encourage these children to develop in the areas where they are strongest.

> ***WARNING:*** Some doctors are quick to treat learning disabilities with medicines– especially when the children are very active. **Use of medicine is often not helpful, and may do more harm than good.** Try to get advice from several experienced persons before giving any medicines.

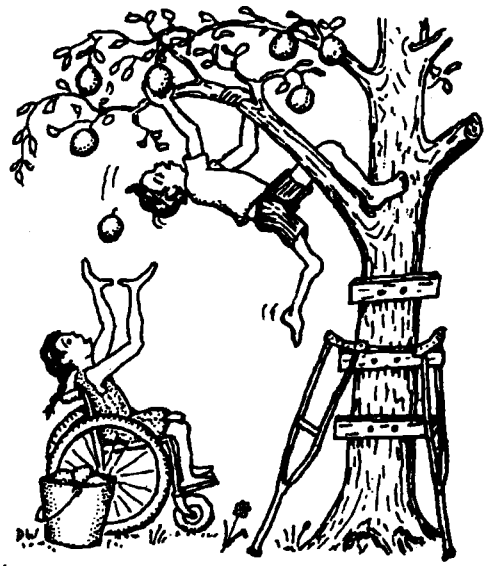
NOTES

CHAPTER 43

Range-of-Motion and Other Exercises

All children need exercise to keep their bodies strong, flexible, and healthy. Most village children get all the exercise they need through ordinary daily activity; **crawling, walking, running, climbing, playing games, lifting things, carrying the baby,** and **helping with work** in the house and farm .

As much as is possible, disabled children should get their exercise in these same ways. However, sometimes a child's disability does not let him use or move his body, or parts of it well enough to get the exercise he needs. **Muscles** that are not used regularly grow weak. Joints that are not moved through their full range of motion get stiff and can no longer be completely straightened or bent (see Chapter 8 on **contractures**). so we need to make sure that the disabled child uses and keeps strong whatever muscles he has, and that he moves all the parts of his body through their full range of motion. Sometimes a child may need help with these exercises. But as much as possible, he should be encouraged to do them himself, in ways that are useful and fun.



As much as possible, disabled children should get their exercise in ways that are useful and fun!

Different exercises for different needs

Different kinds of exercises are needed to meet the special needs of different children. On the next two pages we give an example of each kind of exercise. Then we look at some of the different exercises in more detail.

Purpose of exercise	Kind of exercise	Pages with good examples
To maintain or increase joint motion	1. range-of-motion exercises(ROM) 2. stretching exercises	266, 456, 466 93, 456, 471
To maintain or increase strength	3. strengthening exercise **with motion**; exercises that work the muscles and move the joint against resistance	456, 466, 476
	4. Strengthening exercises **without motion**; exercises that work the muscles without moving the joint	160, 161,456
To improve position	5. practice at holding things or doing things in good positions	107, 169, 184
To improve control	6. practice doing certain movements and actions, to improve balance or control	376, 397, 457

DIFFERENT KINDS OF EXERCISES AND WHEN TO USE THEM

1. Range–of–motion exercises (ROM)

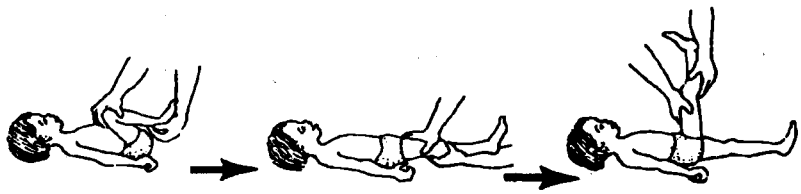
Ram is 2 years old. Two weeks ago he became sick with polio and both legs became paralyzed.



Ram needs range–of–motion exercises to **keep the full motion of his joints**, so they will not develop contractures (see p. 458).

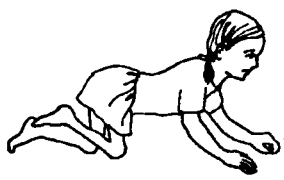
At least 2 times a day, his mother slowly bends, straightens, and moves all the joints as far as they normally go.

All these are exercises for his knee. For other ROM exercises he needs, see p. 466 to 469.

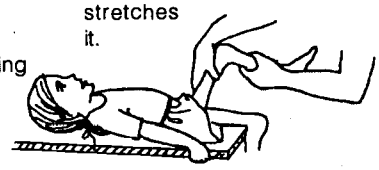


2. Stretching exercises

Rita, who is now 4, had polio at age 2. She did not have any exercises to keep the range of motion in her joints, and now she has severe **contractures** especially of the knees.



Rita's mother does stretching exercises several times a day, to straighten the joints a little more each day. Stretching exercises are like ROM exercises, but the joint is held with firm, steady pressure in a position that slowly stretches it.

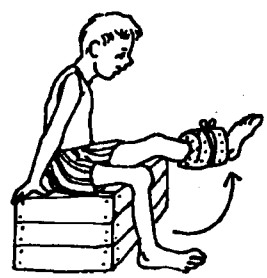


3. Strengthening exercises with motion



Manu was 6 years old when he got his clothes and body wet with a poison his father used to kill weeds. A week later his legs became so weak he could not stand. Now, 2 months have passed, and Manu is a little stronger. But he still falls when he tries to stand.

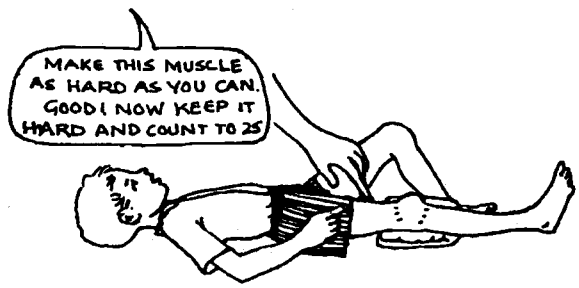
To help strengthen the weak muscles in his thighs, Manu can raise and lower his leg like this–first without added weight and later with a sandbag on his ankle. As his leg gets stronger the weight can be increased.



4. Strengthening exercises without motion

Usha, who is 9 years old, has a very painful knee. It hurts her to move it and her thigh muscles have become so weak she cannot stand on the leg. She cannot do exercises like Manu does because it hurts her knee too much.

But Usha can do exercises to strengthen her leg without moving her knee. She holds it straight and tightens the muscles in her thigh.



For more information on 'exercises without motion' see p. 160.

5. Exercises to improve position

Mathew is 8 years old and has early signs of muscular dystrophy. Among other problems, he is developing a sway back.



Ask Mathew to stand against a wall and to pull in his stomach so that his lower back comes as close to the wall as possible. Ask him to try to always stand that way, and praise him when he does.



Because sway back is often partly caused by weak stomach muscles, strengthening the stomach muscles by doing 'sit-ups' may also help. See if Mathew can still do sit-ups-at least part way, and have him do them twice a day.

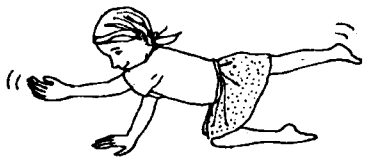
It is best to do sit-ups with the knees bent, (With legs straight, the hip- bending muscles may do more work than the stomach muscles.)



6. Exercises to improve balance and control

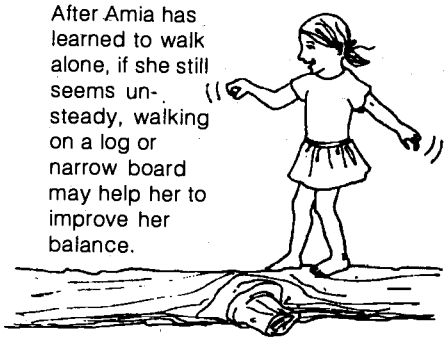
Amia is 3 and still cannot walk without being held up. She has poor balance. Many exercises and activities might help her improve her balance and control of her body. Here are 2 ideas for different stages in her development. For other possibilities, see Chapter 36 on Early Stimulation.

Play games with her to see if she can lift one leg, and then the other.



This will help her shift her weight from side to side and keep her balance.

After Amia has learned to walk alone, if she still seems unsteady, walking on a log or narrow board may help her to improve her balance.



COMBINED EXERCISES

Often several kinds of exercises, involving different parts of the body, can be done through one activity–often an ordinary activity that children enjoy.

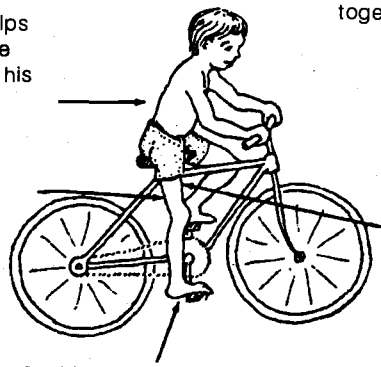
For example, Balu, who is 8 years old, has polio as a baby. His right leg is weak, his knee does not quite straighten, and the heel cord of his right foot is getting tight. He is also developing a sway back.



Many of the exercises Balu needs he can do by riding a bicycle.

The biking position helps **improve the position** of his back.

Learning to ride improves **his balance and his control**, so that all parts of his body work smoothly together.



The movement of pedaling gives **range-of-motion** and **stretching** exercises to his knee.

Pushing the pedal down **strengthens** the thigh muscle.

Pushing down on the pedal **stretches** the tight heel cord.

Note: Ordinary activities that exercise the whole body, like riding a bicycle or swimming, can provide many of the exercises that a child needs. But sometimes specific exercises using special methods are needed. Some special exercises are included in this chapter.

RANGE-OF-MOTION (ROM) EXERCISES

What are they?

Range-of-motion exercises are regularly repeated exercises that straighten or bend one or more joints of the body and move them in all the directions that a joint normally moves.



Why?

The main purpose of these exercises is to keep the joints flexible. They can help prevent joint stiffness, contractures and deformities.

Range-of-motion exercises are especially important for **prevention of joint contractures**. This danger is greatest when paralysis or spasticity causes '**muscle imbalance**'–which means the muscles that pull a joint one way are much stronger than those that should pull it the other way, so that the joint is continuously kept bent or kept straight (see p. 88).

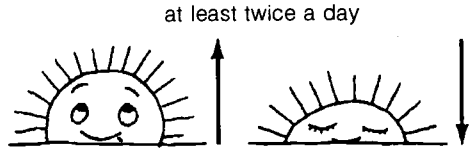
Who should do them ?

Range-of-motion exercises are important for:

- babies born with cerebral palsy, spina bifida, club feet, or other conditions that may lead to gradually increasing deformities.
- persons who are so sick, weak, or badly injured that they cannot get out of bed or move their bodies very much.
- persons who have an illness or injury causing damage to the brain or ***spinal cord***, including :
  - polio (during and following the original illness)
  - meningitis or encephalitis (***infections*** of the brain)
  - spinal cord injury
  - stroke (paralysis from bleeding or blood clot in the brain, mostly in older adults, see ***Where There Is No Doctor***, p. 460)
- children with parts of their bodies paralyzed from polio,injury, or other causes, especially when there is muscle imbalance,with risk of contractures.
- children with ***progressive*** nerve or muscle disease, including muscular dystrophy and leprosy.
- children who have lost part of a ***limb*** (amputation).

How often?

ROM exercises should usually be done at least 2 times a day. If some joint motion has already been lost and you are trying to get it back, do the exercises more often, and for longer each time.



When should range–of–motion exercises be started?

Early! Start before any loss in range of motion begins. With gentleness and caution, help a severely ill or recently paralyzed child to do range–of–motion exercises from the first few days. For precautions, see p. 462 to 464. **Starting range–of–motion exercises EARLY can reduce or prevent disability.**



RAVI AND NOOR



Ravi and Noor got meningitis on the same day. With quick, good medical treatment both survived. But both has suffered brain damage that left their bodies stiff and bent.

From the time his fever dropped, Ravi's mother did exercises with him– 2 times every day.

As he got better, she also played with him a lot– in ways that helped him stretch and bend all joints as much as possible.



Little by little Ravi's body began to loosen up

Noor's mother cared for her child as best as she could, but no one told her about exercises.



Noor's body became more and more tight and bent.

In both children the muscle spasms gradually went away. By 6 months both could control their body movements almost normally.

Because Ravi's joints were kept flexible, as his muscle control came back he learned to use his body nearly as well as any child his age.



It is much easier to prevent these problems than to correct them

RESULTS WITH AND WITHOUT RANGE OF MOTION EXERCISES

When Noor's muscle control returned, his muscles had shortened so much that he could not straighten his hips or knees enough to walk. He could only crawl, and his body became more and more deformed.





For how long should range–of–motion exercises be continued?

To prevent contractures or deformities, **range–of–motion exercises often need to be continued all through life.** Therefore it is important that a child learn to **move the affected parts of his body through their full range of motion as part of work, play, and daily activity.** If the range of motion remains good, and the child seems to be getting enough motion through daily activities, then the exercises can be done less often. Or simply check every few weeks to be sure there is no loss in range of motion.

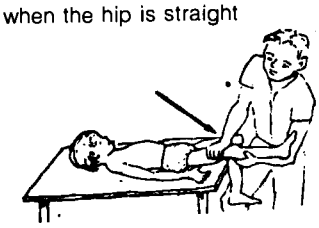
Which joints ?

Exercise all the joints that the child does not move through normal range of motion during her daily activities. For a child who is very ill or newly paralyzed, this may mean **exercising all the joints of the body**. For a child with one paralyzed limb, range–of–motion exercises usually only need to be done with that limb (including the hip or shoulder). Children with arthritis may need range–of–motion exercises in all their joints, including the back,neck and even jaw and ribs.

GUIDELINES FOR DOING STRETCHING AND RANGE-OF-MOTION EXERCISES

1. When doing these exercises, **consider the position of the whole child**, not just the joint you are moving. For example:

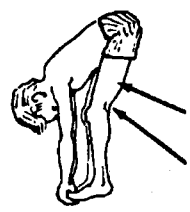
The knee will often straigthen more (and yo will be stretching different muscles) when the hip is straight



than when the hip is bent



This is because some muscles go from the hipbone to below the knee.



To prove this, try to touch your toes with your knees straight. You will feel the muscles stretchand the cords tigthen here.

In a similar way, movement in the ankle is affected by he position of the knee (see p.20) and movement of the fingers by the position of the wrist(see p. 463)

2. If the joints are stiff or painful, or cords and muscles are tight, often it helps to **apply heat to the joint and muscles** before beginning to move or stretch them. Heat reduces pain and relaxes tight muscles. Heat can be applied with hot water soaks, a warm bath, or hot wax. For methods,see p. 152 and 153.

For a stiff, painful joint



apply heat for 10 or 15 minutes



before doing the exercises



3. **Move the joint SLOWLY through its complete range of motion**

If the range is not complete, try to stretch it slowly and gently just a little more each time. Do not use force, and stop stretching when it starts to hurt.

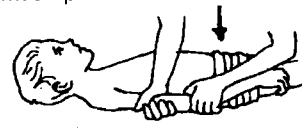
Hold the limb in a stretched position while you count to 25.



Then slowly stretch the joint a little more and hold it again for a while.



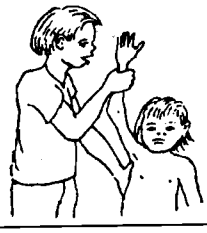
Continue this way until you have stretched it as far as you can without forcing it or causing much pain.



The more often you repeat this, the faster the limb will get straigter.

4. **Have the child herself do as much of the exercise as she can**. Help her only with what she cannot do herself. For example:

Instead of doing the child's range-of-motion exercise for her,



have her do the exercise using her own muscles as much as she can →



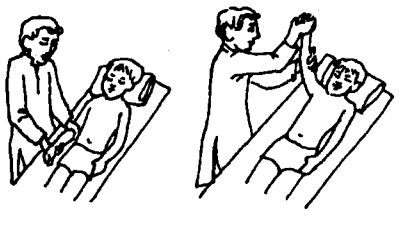
Then have her help with the other hand (or you help her if necessary). →



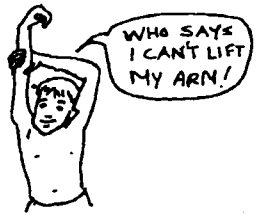
Whenever possible, exercises that help to **maintain or increase joint motion** should also help to **maintain or increase strength**. In other words, **range-of-motion, stretching and strengthening exercises can often be done together.**

THERE ARE 3 MAIN WAYS OF DOING RANGE-OF-MOTION EXERCISES

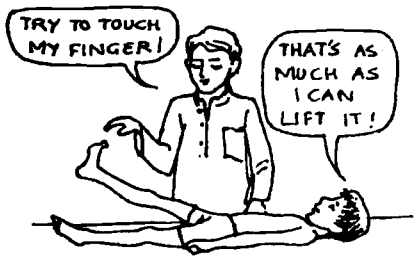
1. **Passive exercise** If the child cannot move the limb at all, either you can do it for him.



or he can move the limb through its full range with another part of his body.



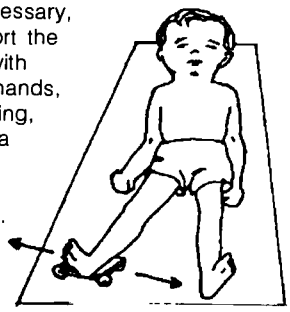
2. **Assisted exercise.** If the child has enough strength to move the affected part of her body a little, have her move it as far as she can. Then help her the rest of the way.



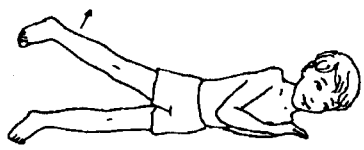


3. **Active exercise.** If the child has enough strength to move the body part by itself through its full, normal range of motion, then he can do the exercises without assistance, or actively'. When the child can do it, **active exercise is usually best, because it also helps maintain or increase strength.**

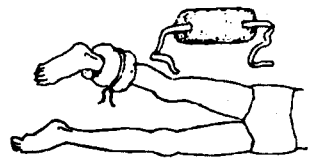
If muscle strength is poor, have the child move his limb while in a position so that he does not have to lift its weight. If necessary, support the limb with your hands, in a sling, or on a small roller board.



If he can lift the weight of his limb through its full range of motion, let him exercise in a position to do it. For example, he can lie on his side and lift his leg up sideways.



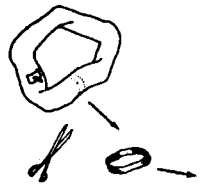
If he can lift the limb's weight easily, add resistance by pushing against the limb or by tying a sandbag to it. This helps strengthen the muscles for that motion.

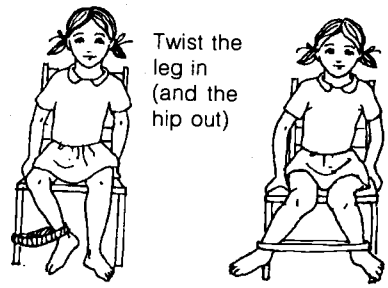


cloth bag fitted with sand.

As the child gains strength, gradually increase resistance (add more weight).

For many exercises, resistance can be added with **stretch bands.** Cut rubber bands from an old inner tube. The wider the band, the more resistance it will give.





Twist the leg in (and the hip out)

Twist the leg out (and the hip in).

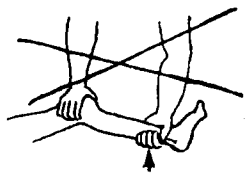
This child is doing range-of-motion and strengthening exercises at the same time.

COMMON SENSE *PRECAUTIONS* WHEN DOING EXERCISES

Every child's needs are different. Please do not simply do, or recommend, the same exercises for each child. First THINK about the child's problems and needs, what exercises might help her most, and what could possibly harm her. **Adapt the exercises to the child's needs, and how she responds.** Here are some important precautions:

1. **Protect the joint.** Weak joints can easily be damaged by stretching exercises, unless care is taken. **Hold the limb both above and below the joint** that you are exercising. And **support as much of the limb as you can.**





WARNING: Pulling here can dislocate the knee (or break the bone).

WARNING: Moving spastic joints rapidly makes them stiffer. SLOW DOWN!

2. **Be gentle–and move the joints SLOWLY–** especially when a child has spasticity, or when joints are stiff or painful.

For example, Teresa has juvenile arthritis and her joints are very painful. She holds them in bent positions that are leading to contractures. Move the joints very slowly and gently, as far as you can without causing too much pain. Straighten them little by little, like this :





A common mistake is to rapidly move the limb back and forth like the handle of a pump. This does no good and can do harm. **Go slow, with gentle, steady pressure.**

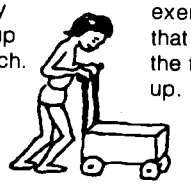
3. **Do no harm.** In children who have recently broken their neck,back or other bones, or who have serious injuries, exercises should be done with great caution. Be careful not to move the broken or injured part of the body. This may mean that some joints cannot be exercised until the bones have joined or wounds healed.(For broken bones, usually wait 4 to 6 weeks).

4. **Never force** the motion. Stretching will often cause discomfort, but it should not be very painful. If the child cannot tell you, or does not feel, be extra careful. Feel how tight the cords are to be sure you do not tear them.



5. **Do not do exercises that will increase the range of motion of joints that are 'floppy' or that already bend or straighten more than they should.**

If a child has ankles that already bend up too much, do *not* do ROM or stretching exercises that pull the foot up.

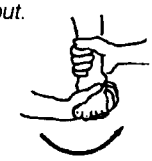




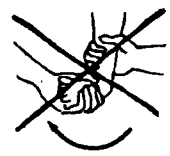
Or, if a child's foot bends *in* more than normal, but does not bend *out*.



do exercises to bend the foot *out*.



but do *not* do exercises that bend the foot *in*.



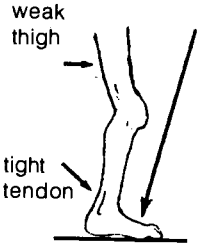
Do exercises in the opposite direction of the deformity or contracture, so that they help to put the joint into a more normal position.

6. Before doing exercises to increase the range of motion in certain joints, **consider whether the increased motion will make it easier for the child to do things**. Sometimes certain contractures or joint stiffness may actually help a child to do things better.

For example a child with a short leg may walk better if a tight heel cord keeps his foot in a tiptoe position.



Similarly, a child with paralysis in the thigh muscles may actually walk better if a tight heel cord prevents his foot from bending up. (See p. 643.)



This foot does not bend up. The tight heel cord holds the leg back and keeps the knee from bending.



Stretching exercises to bend the foot up may cause the weak knee to bend when the child tries to walk.

A child with cerebral palsy or arthritis often needs exercises to maintain or improve the movement of the back. However, a child with spinal cord injury or muscular dystrophy may do better if the back is allowed to stay stiff– especially if it is in a fairly good position.

Because of their weak back muscles, these children often develop a slouched or hunchback position. **Range–of–motion exercise to increase flexibility could make the posture worse !**



with ROM back exercise

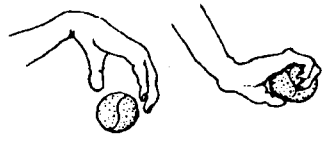
Allowing the child's back to stiffen in a good position may help him to sit straighter.



without ROM back exercise.

In persons with **quadriplegia** or other paralysis that affects the fingers, **avoid stretching open the fingers with the wrist bent back.**

A quadriplegic person with no muscle power in his fingers can often pick things up by bending the wrist back. Tight cords make the fingers bend.





RIGHT

To keep this holding function, straighten fingers with wrist bent down,

WRONG

Do not stretch the fingers with the wrist bent back.



For the same reason, the quadriplegic child should also learn to support herslef on her hands with her fingers bent, not straight.



RIGHT

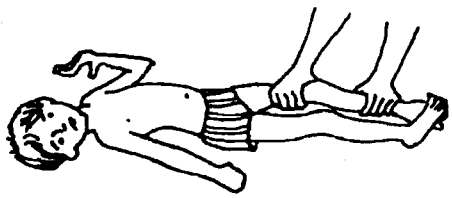


WRONG

7. In doing range-of-motion exercises for a stiff neck, caution is needed to make the neck bones do not slip and cause damage to the **spinal nerves**. This damage cause total paralysis or even death. The danger is especially great in persons with arthiritis, Down syndrome, or neck injury. **Do not use any force to help the person bend her neck. Let her do it herself slowly, with many repetitions, and without forcing.**

8. (CP) In children with **cerebral palsy**, sometimes the **standard range-of-motion exercises will increase spasticity** and make bending or straightening of a particular joint difficult or impossible. Often the spastic muscles can be relaxed by **positioning** the child in a certain way before trying to exercise the limb. For example:

When a child with spasticity lies straight his back, his head and shoulders may push back. His legs also stiffen and will be hard to bend.



It may be very hard to bend the spastic legs of a child in this position.

But if we position the child with his back, shoulders, and head bent forward, this helps to relax his stiff legs and will make motion easier.

It may also help to rotate the leg outward before trying to bend the knee.



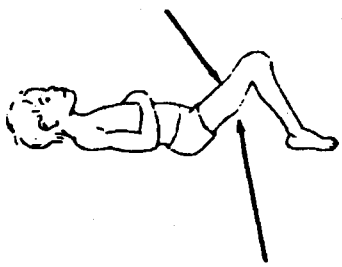
A hammock is good for positioning the child with cerebral palsy who stiffens backward.

REMEMBER: Fast movements increase spasticity.
Do exercises VERY SLOWLY.

CAUTION; **Range-of-motion exercises are very important for many children with spasticity**, but special techniques are needed. More examples of how to relax spasticity are given in Chapter 9 on cerebral palsy. However, you can learn a lot by trying different positions until you find the ones that help relax the spasticity.

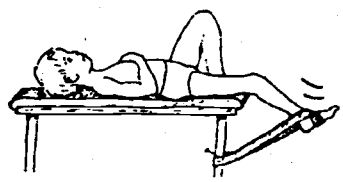
9. In joints where there is **muscle imbalance** (see p. 88), **do exercises to strengthen the weaker muscles, not the stronger ones.** This will help to prevent contractures by making the muscle balance more equal.

If the muscles that straighten the knee are weak



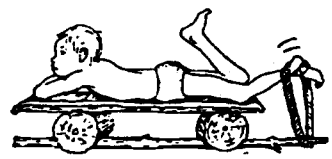
and the muscles that bend the knee are strong.

then do exercises that strengthen the weaker side



This will make stronger the muscles that straighten the knee. It helps prevent contractures.

Do **not** do exercises that strengthen the stronger side.



This will make the muscles stronger that bend the knee-and make contractures more likely.

In daily activities, also look for ways to give weak muscles more exercise than strong ones. This advice is discussed in more detail in Chapter 16 on juvenile arthritis.

IDEAS FOR MAKING EXERCISES FUN

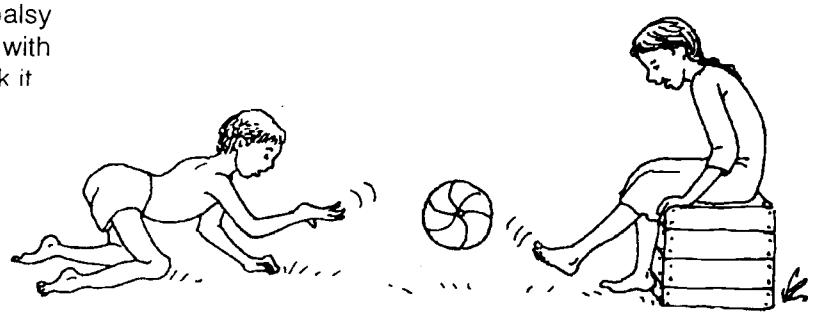
Exercises can quickly become boring, and the child will not want to do them. So turn them into games whenever possible.



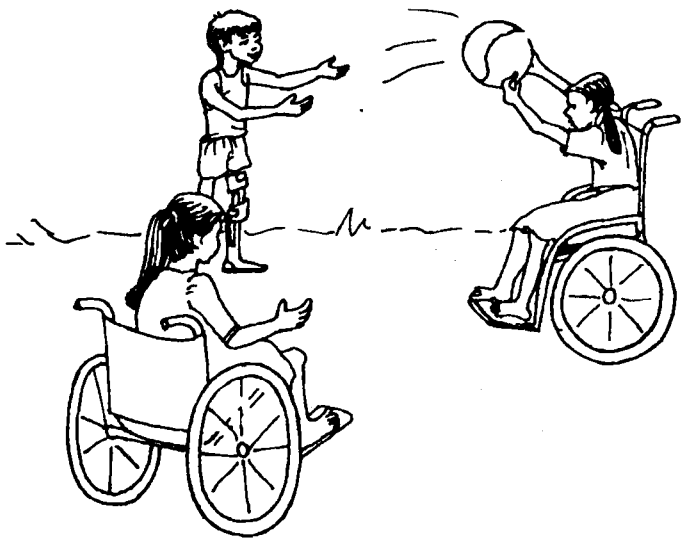


One good way is to involve the children in games with other children. Try to think of ways to **adapt games so that they help to stretch the joints and exercise the muscles that most need it.**

A boy with cerebral palsy rolls a ball so that a girl with juvenile arthritis can kick it. This helps her to straighten her knees, and to strengthen her knees, and to strengthen the muscles that straighten them.



In the picture below, children play ball to help Maria, a girl with juvenile arthritis, stretch her stiff joints and muscles.



Can you see how the 2 children on the left are helping Maria with range-of-motion exercises?

Which of Maria's joints are they exercising?

Answers:

The children form a triangle, so that to catch the ball Maria has to twist her body to ne side, and to throw it she has to twist to the other side. This helps loosen her stiff back and neck. Also, sometimes they throw the ball high so that she has to lift her head and raise her arms high to catch it.

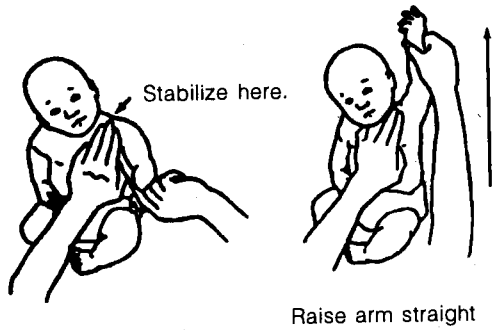
This way Maria exercises her neck, back, shoulders, elbows, wrists,hands, and fingers. And the play helps her forget the pain of movement-pain that often makes range-of-motion exercises seem like punishment. But this way she has fun.

Complete range–of–motion exercises–upper limbs*

Do these exercises slowly and steadily. Never use force, as this could damage a joint.

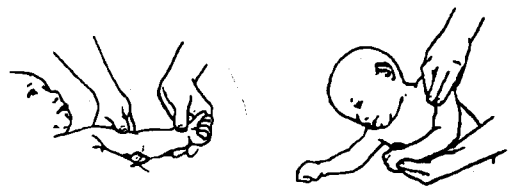
Do one joint at a time. Hold the limb steady (stabilize it) with one hand just above the joint, and place your other hand below the joint to move the part through its full range of motion. Here we show the basic exercises only. But remember, try to do them in ways that make it fun!

SHOULDER: arm up and down



Raise arm straight forward, and up.

SHOULDER: arm back and forward



Move arm all the way back,

and then all the way forward over the chest.

SHOULDER: rotation

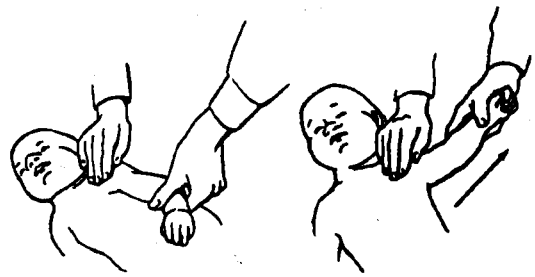


with elbow bent

turn the arm all the way up

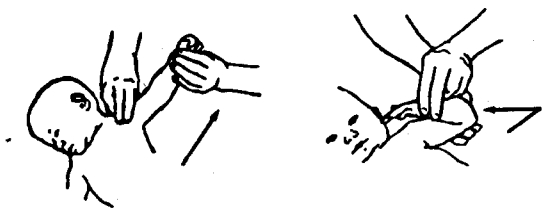
then all the way down.

SHOULDER: out to side



Raise arm straight out to side.

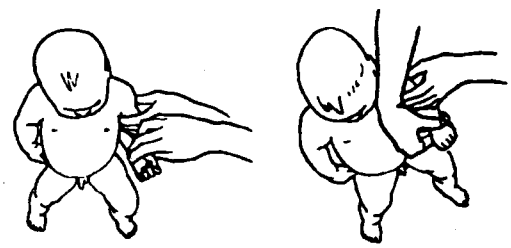
ELBOW: straighten and bend



Straighten the arm out from the side,

then bend the elbow to bring up to shoulder.

FOREARM: twist



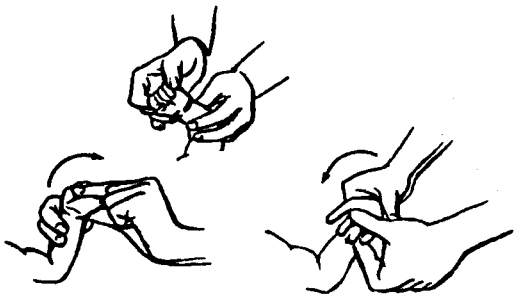
Holding the wrist twist the hand up,

and then twist it down (gently).

*Drawings on pages 466 to 468 are adapted from Range–of–Motion by Hewitt/Jaeger.

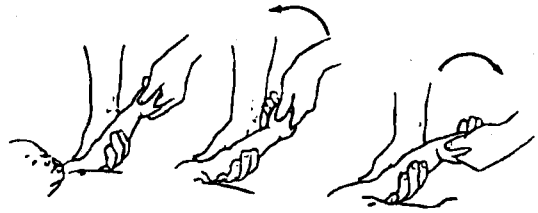
(See p. 772.)

WRIST: up and down



Bend wrist back, and then forward.

WRIST: side to side



Bend to outside.

Bend to thumb side. (It will not bend very far to thumb side. Do not force.)

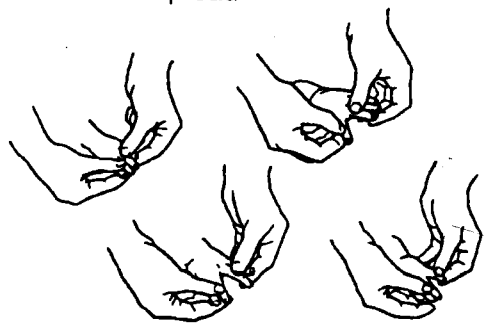
FINGERS: close and open



Make a fist

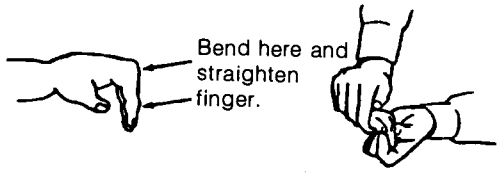
Straighten gently.

FINGERS: spread

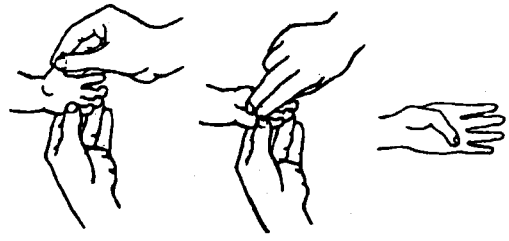


Spread each finger one at a time

FINGERS: straighten while bent at hand

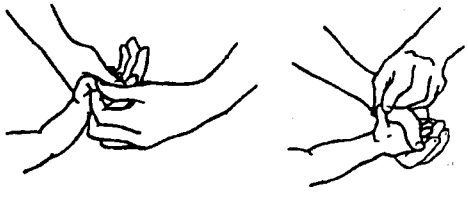


THUMB: for grasping



Bend thumb toward base of little fingers.

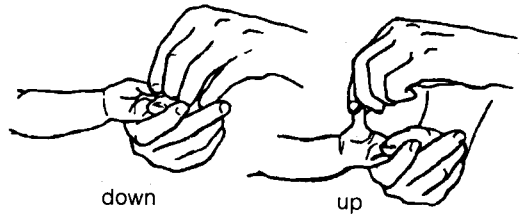
THUMB: shut and open



Bend the joints of the thumb in all the way,

then open thumb all the way to the side.

THUMB: up and down



Move straightened thumb down and then up, with palm flat and fingers open.

Range–of–motion exercises–lower limbs

(Also see the exercise sheets on pages 470 to 474.)

KNEE

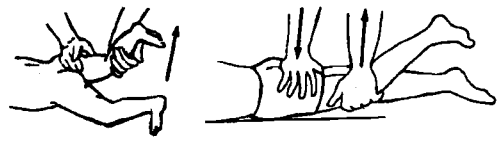


Bring heel back as far as possible, then straighten leg as much as possible

HIP: straightening

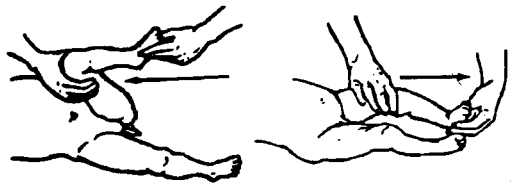
(Also see p. 473.)

in an older child



Be sure hip stays flat against a firm surface as you bend leg up.

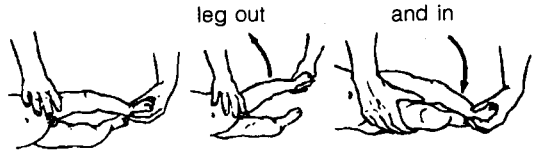
HIP : bend



Bend knee to chest. Straighten all the way.

HIP : spread

leg out and in



Spread hips open as far as you can by moving leg out to the side.

HIP: twisting (rotation) –leg straight

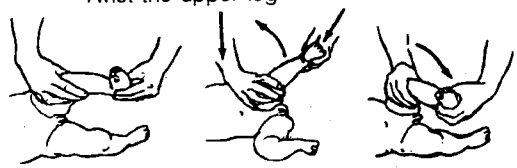
Twist the leg not the foot



Roll leg and foot to inside, then to outside.

HIP ROTATION: leg bent

Twist the upper leg not the foot



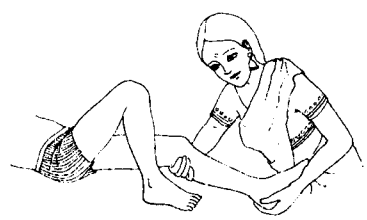
With knee bent, swing leg out, then in

ANKLE TWISTING: (Also see p. 93.)



Bend foot down. Pull heel down and bend foot up.

IMPORTANT: To stretch a tight heel cord, pull heel down as you push foot up.



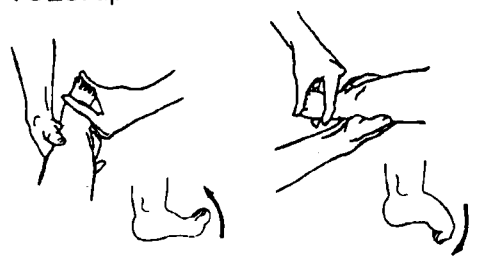
Pull heel harder than you push on foot–or you may dislocate foot upward instead of stretching the ankle cord and muscles. (See p. 470 and 471.)

ANKLE TWISTING: in and out



Twist in. Twist out.

TOES: up and down

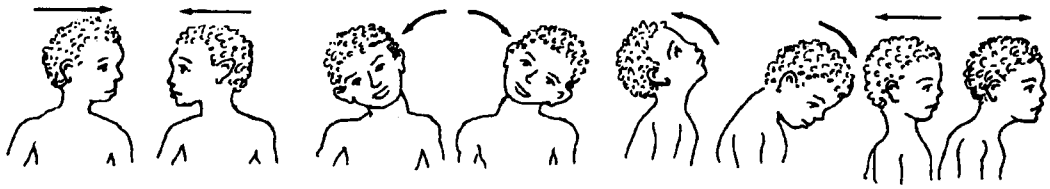


Bend toes up. Bend toes down.

Range–of–motion exercises–neck and trunk

We show these as active exercises. Usually they should be done by the person himself. if any help is given it should be very gentle, with no force, especially when exercising a stiff neck (See precaution on p. 464)

NECK



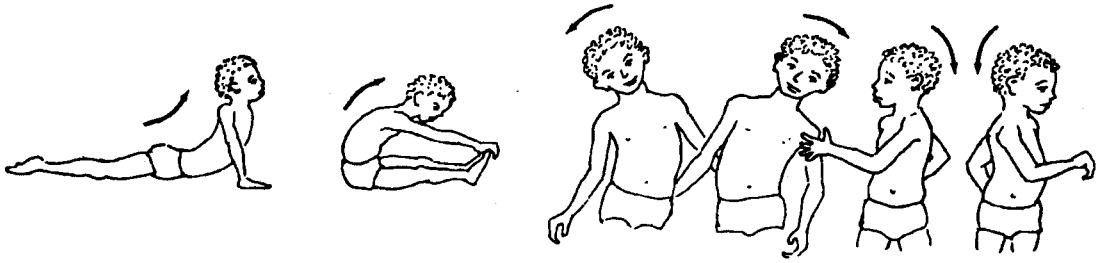
Turn head to left and to right

side to side,

up and down,

and back and forward

TRUNK



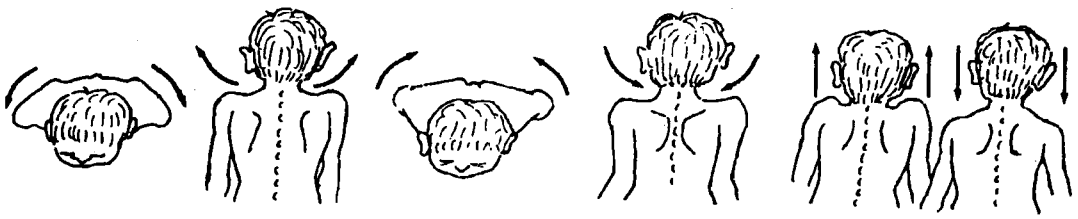
Bend back.

Bend forward.

Bend sideways.

Twist

UPPER BACK: (shoulder blades)



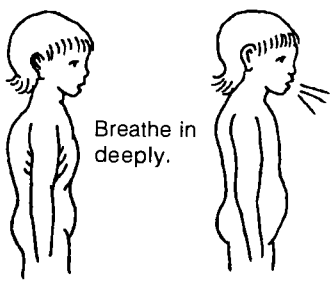
Bringing shoulders forward, pulls the shoulder blades wide apart.

Pulling shoulders back, pushes the shoulder blades close together.

Pull shoulders up toward ears.

Push shoulders down.

RIBS



Breathe in deeply.

Breathe out deeply. see how long you can whistle or blow.

(Blow a whistle or blow up a balloon.)

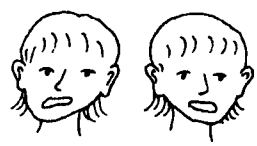
JAW



Pull jaw back.

and push forward.

Open mouth wide.



Move jaw to one side.

and then to the other side.

EXERCISE INSTRUCTION SHEETS– For Giving To Parents

If you give the family pictures of the exercises that their child needs, they will be more likely to do them–and do them right.

On the next few pages are samples of **exercise sheets** that you can copy and give to families. They show some of the bone exercises that we have found are needed most often.

However, these exercise sheets should not be a substitute for hands-on demonstration and guided practice. Instead, **give them to the family after you teach them how to do the exercises**. In teaching an exercise or activity:

1. First show and explain.



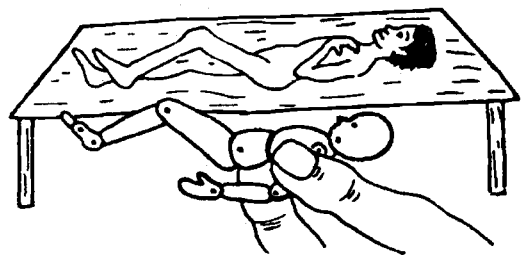
2. Next have the family and child practice until they do it right and understand why.



3. Then give her the instruction sheets and explain the main ideas again.



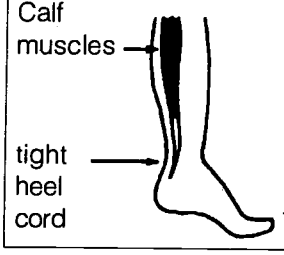
4. For exercises to correct contractures, consider giving the family a 'flexikin'. Show them how to measure and record the child's progress. This lets them 'see' the child's gradual improvement, so they are likely to work harder at the exercises. (See "Flexikins" in Chapter 5).



You may want to prepare more sheets showing other exercises, activities, or play ideas that are included in this book. Better still, make sheets showing **exercises and activities in ways that fit your local customs and that help the child to take part in the life of the community.** (See Chapters 1 and 2.)

STRETCHING EXERCISE–TO HELP YOUR CHILD PUT HER FOOT DOWN FLAT (TO CORRECT A 'TIPTOE' CONTRACTURE)

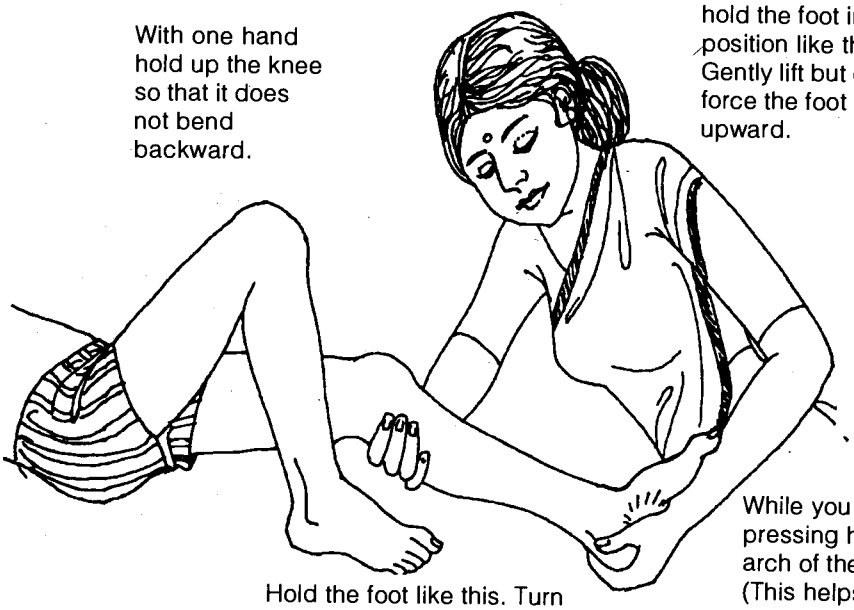
EXERCISE SHEET 1



PROBLEM

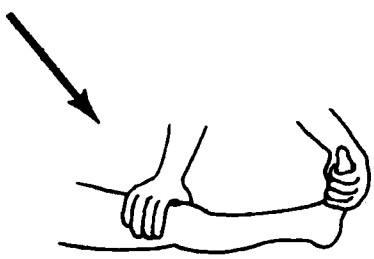
The muscles at the back of the lower leg (calf muscles) that hold the foot 'tiptoe', are too short and tight.

For this reason the child cannot put her foot flat on the ground.



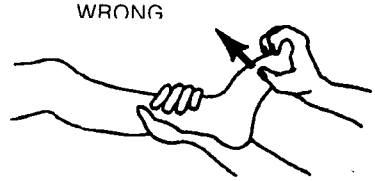
Pull down on the heel and push up on the foot, firmly and steadily while counting slowly to 25. Relax, then do it again. Repeat this exercise 10 to 20 times– in the morning at noon, and in the evening.

WARNING: Pushing here can injure the knee or cause it to bend backward–especially if the upper leg is weak.



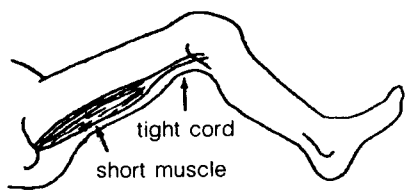
Pushing like this can hurt or dislocate the foot instead of stretching the cord–especially if the foot is paralyzed or very weak.

WRONG



STRETCHING EXERCISE–TO STRAIGHTEN A STIFF KNEE (KNEE CONTRACTURE)

EXERCISE SHEET 2



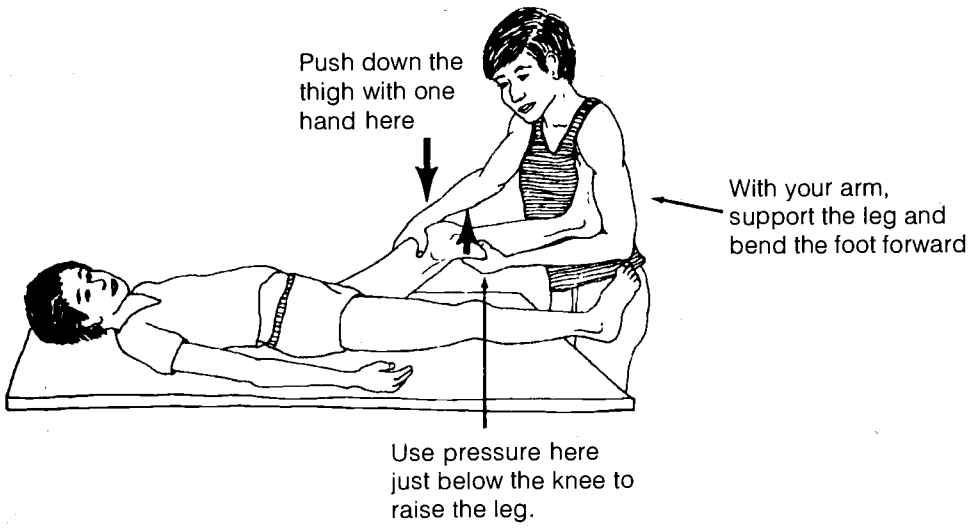
PROBLEM

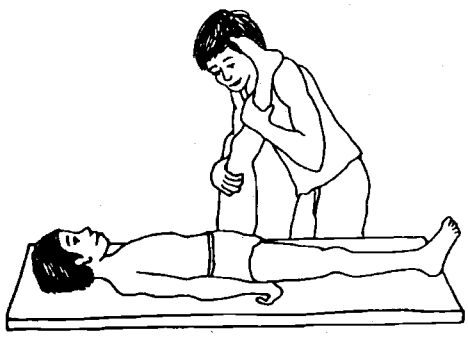
The muscle and cord here are too short and tight. For this reason the knee will not straighten.

Ask the child to straighten his knee as much as he can by himself (if he can do it at all). Then help him slowly straighten it as far as it will go.

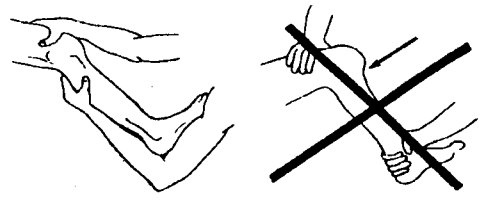
Both of you keep working to hold the knee as straight as possible while you count slowly to 25. Repeat several times. Do this exercise 3 times a day.

If the foot also has a contracture, try to hold or bend it up while you stretch the cord behind the knee.





When you get the knee as straight as you can with the hip extended, gradually lift the leg higher, keeping the knee straight.



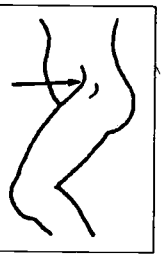
BE CAREFUL. Never try to straighten the leg by pulling the foot. Instead of stretching the cord, this could dislocate the knee or break the leg. The danger is especially great when the leg is very weak or when the child cannot walk.

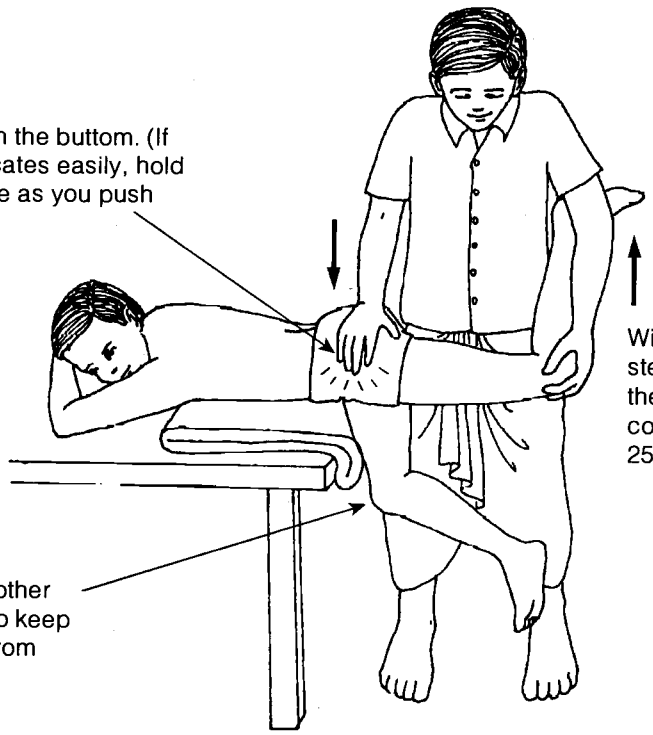
STRETCHING EXERCISE–FOR A BENT–HIP CONTRACTURE

EXERCISE SHEET 3

PROBLEM

The thigh is pulled forward by tight cords and cannot straighten background.

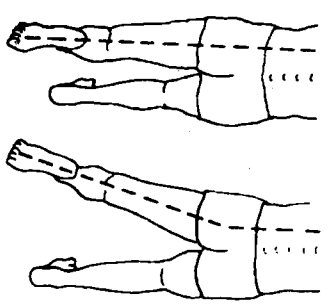




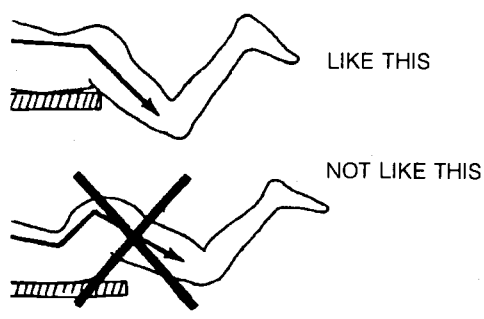
Repeat several times. Do this exercise 3 or more times a day.

VIEW FROM ABOVE

Do the exercise with the leg in a straight line with the body.



Make sure the hips are against the table and that they do not lift up as the leg is lifted.

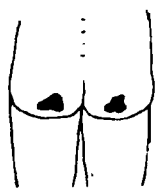


EXERCISES AND POSITIONS TO HELP AVOID PRESSURE SORES AND CONTRACTURES

EXERCISE SHEET 4

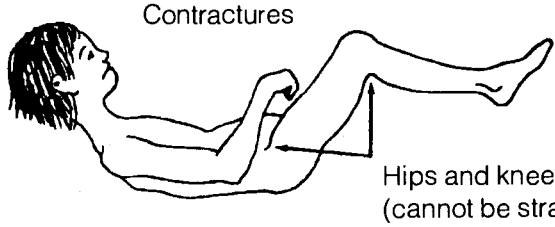
Children who spend a lot of time lying or sitting, or have lost feeling in their buttocks, should NOT SPEND ALL DAY SITTING DOWN. This can cause pressure sores, contractures of the hips and knees, and back deformities.

PREVENT THIS



Pressure sores

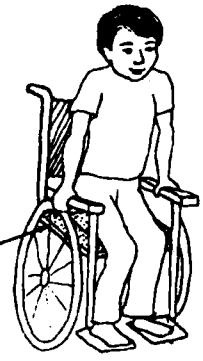
PREVENT THIS



Contractures

Hips and knees are contracted (cannot be straightened) from sitting too much).

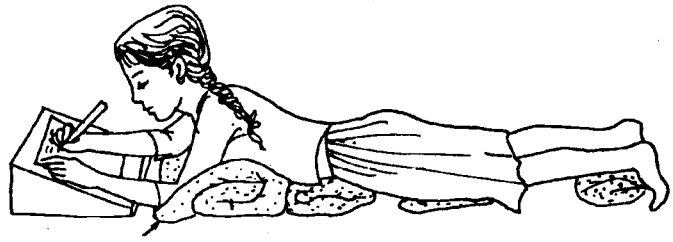
When you spend time sitting in a wheelchair (or any chair) lift yourself up with your arms like this and count to 25 every 15 or 20 minutes.



Be sure to use a soft cushion

Lifting up often is especially important for people who do not have feeling in thier buttock, so that they do not get sores on their bottom.

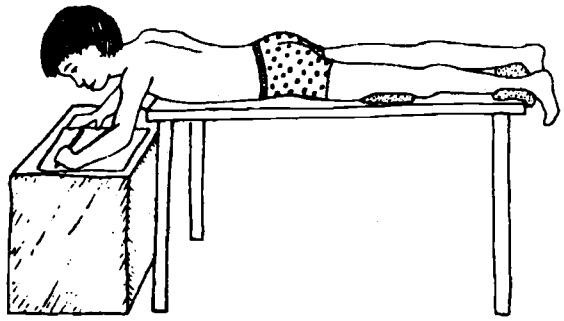
Spend a part of the day lying down with your shoulders up like this. (For other designs see p. 233 and 606.)



cushion or foam rubber wedges

You can do schoolwork lying down. Try to arrange things with the teacher so that you can spend part of your day lying down.

BE CAREFUL: To avoid sores, it is important to put foam rubber cushions to protect the body where bones press against skin–espoecially if you cannot feel in parts of your body.



If the child cannot straighten enough to lie on the floor, he can lie on a table, and work or play with his hands at a lower level, as shown here.

EXERCISE FOR A STRAIGHTER BACK

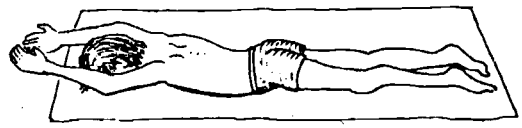
EXERCISE SHEET 5

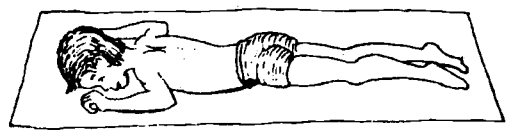


PROBLEM

The upper back bends forward (in older persons this is a common cause of high back pain). Often the shoulders and shoulder blades are also stiff.

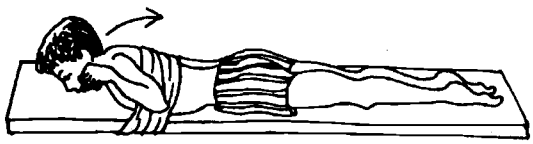
Lie face down and move the arms as shown. This helps keep the shoulder blades and upper back flexible.



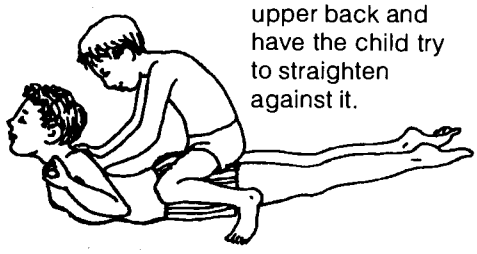




Put a strap around the upper body and bend backward as far as you can.

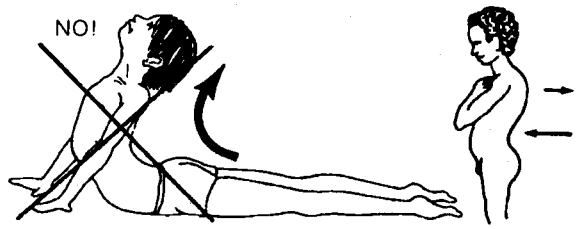


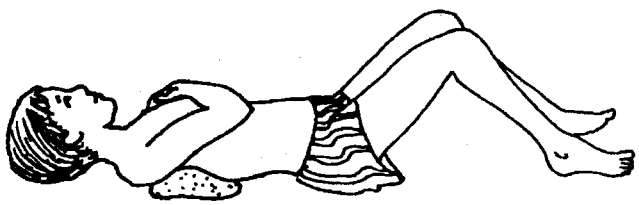
Or put pressure against the middle of the upper back and have the child try to straighten against it.



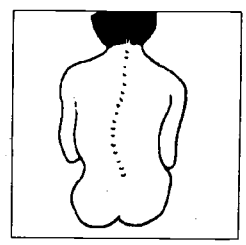
Stay in this position while you count to 25. Do the exercise 2 or 3 times a day.

CAUTION: Bending back like this usually bends the lower back too much and does little or nothing to help straighten the upper back. It may make the problem worse.





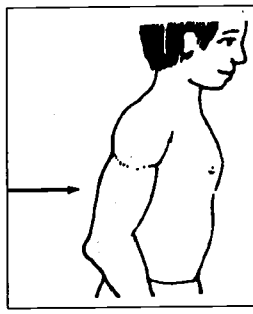
Also, for at least half and hour a day, lie with a rolled up towel or cloth under the middle of the curve in your back. Breathe deeply, and every time you breathe out, try to let you body bend backward over the roll.



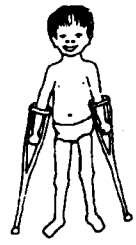
Note: Some experts believe that the exercises that bend the back up and back, as shown above, may also help keep a mild sideways curve of the spine (scoliosis) from getting worse. But the exercises will not help much if the curve is severe.

STRENTHENING EXERCISES–TO GET ARMS READY TO WALK WITH CRUTCHES

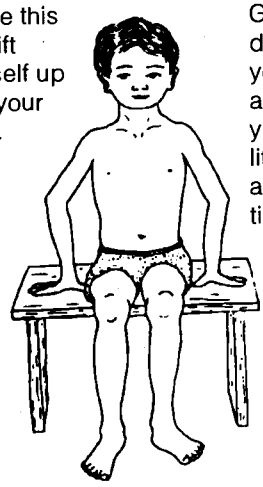
EXERCISE SHEET 6



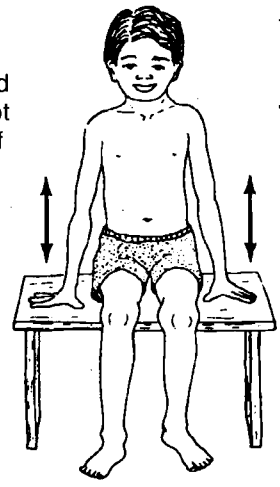
OBJECTIVE
These exercises help make your arms stronger so that you can walk with crutches.



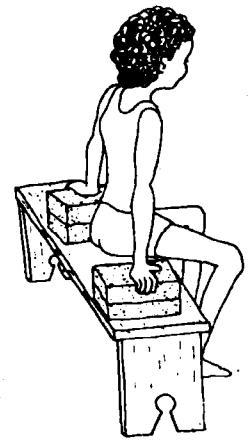
Sit like this and lift yourself up with your arms.



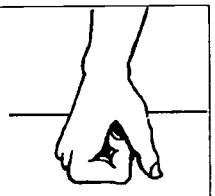
Go up and down until your arms are so tired you cannot lift yourself another time



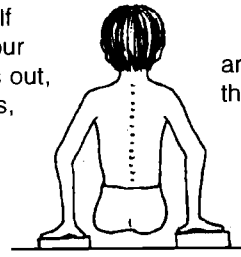
It is better to use bricks or books to lift yourself higher.



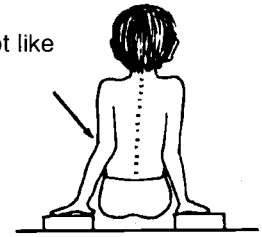
Note: If the child's arms are too short to lift himself up on open hands, he can use his fists.



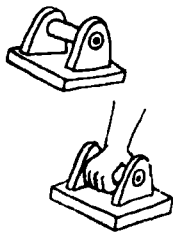
Try to lift yourself with your elbows out, like this,



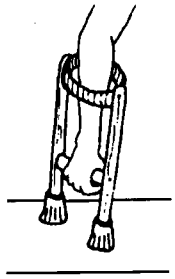
and not like this.



To practice for using crutches, make 'handgrips'.

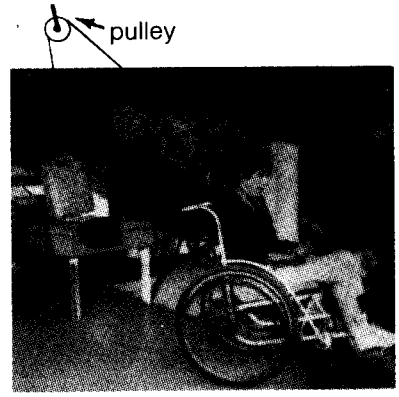


Or use a sawed–off crutch.



Or you can do these exercises in your wheel-chair.





Weight lifting. Increase the weight little as the arms get stronger

Do these exercises 3 or 4 times a day. Every day try to lift yourself more times without resting, until you can do it 50 times.

STRENGTHENING EXERCISE – TO HELP YOUR CHILD HAVE STRONGER THIGHS

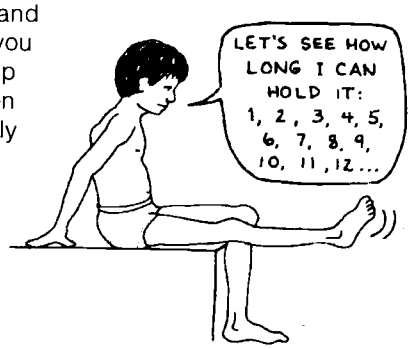
EXERCISE SHEET 7



PROBLEM:

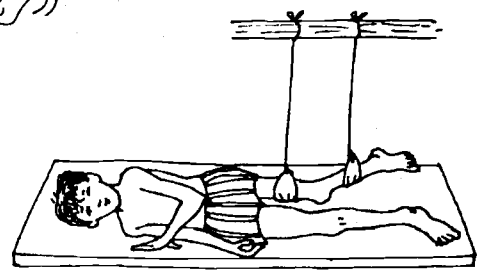
Weak muscles in the front part of the upper leg (thigh muscles) make it difficult to support weight with that leg.

Raise your leg and hold it up until you cannot hold it up any longer. Then lower it as slowly as you can.



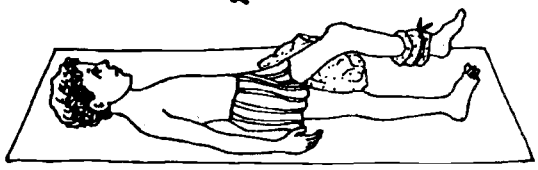
Repeat as many times as possible (until you cannot lift the leg more.)

Do this exercise 2 or 3 times a day.



If the child cannot straighten her leg by herself, help her, but ask her to use all her strength too.

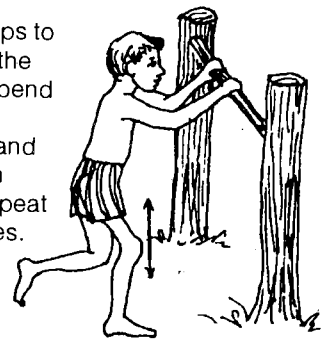


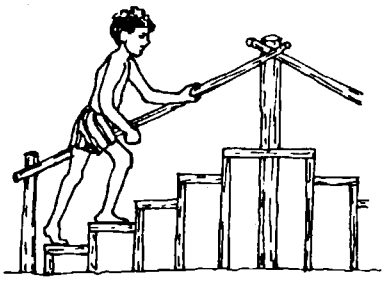


If her thigh is quite weak, have her straighten and bend her leg lying sideways. She may need to have the leg supported.

When this thigh is stronger, put a little bag of sand on his ankle so that he will use more strength to raise it.

It also helps to stand on the leg, then bend as far as possible and straighten again. Repeat many times.

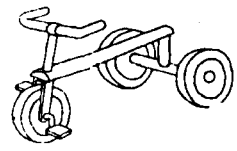






If the leg gets strong enough, practice going up and down steps. Start with low steps and slowly progress to higher ones.

home made tricycle



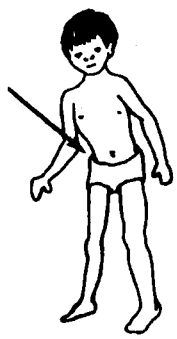
Climbing hills or riding a tricycle or bicycle also helps strengthen the thighs.

STRENGTHENING EXERCISE–FOR THE MUSCLES ON THE SIDE OF THE HIP

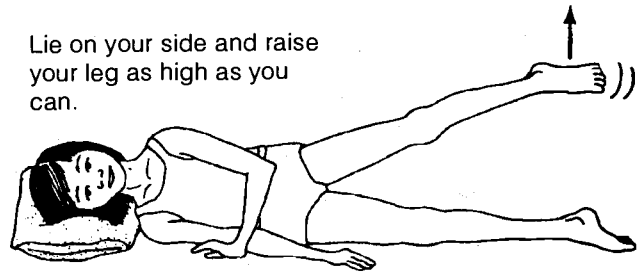
EXERCISE SHEET 8

PROBLEM

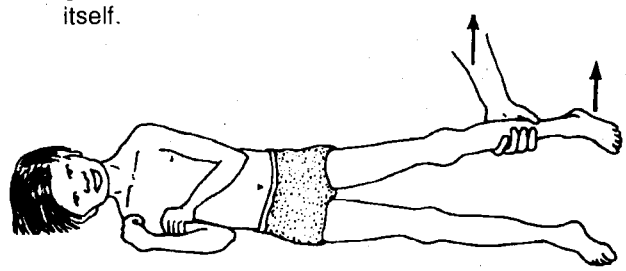
weakness here causes the child to bend to one side when he walks.



Lie on your side and raise your leg as high as you can.

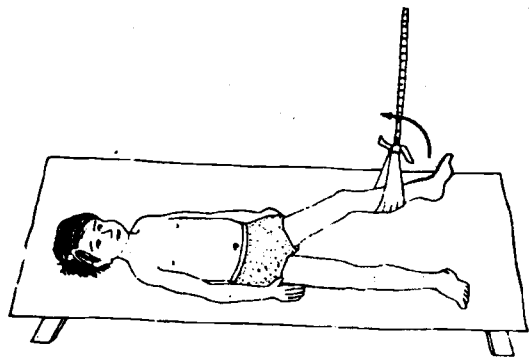


Keep your leg up until you get so tired that it falls by itself.

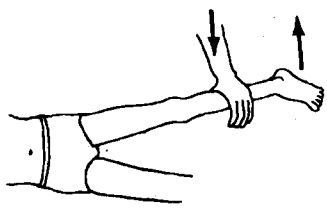


If the child cannot raise his leg by himself, help him a little, but be sure that he uses as much strength as he can

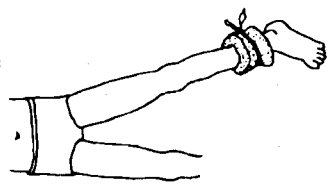
Or have the child lie on his back and move his leg to the side. You can hang the leg like this so that he can move it more easily.



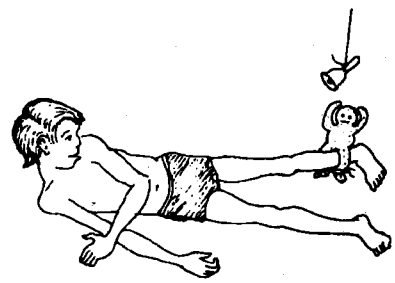
As he gets stronger, move the rope more to the other side to make him work harder.



If the child can raise her leg easily, add weight with your hand,



or with a little bag of sand.



Think of ways to make the exercises fun.

Repeat 3 times. Do this 3 times a day.

RANGE-OF-MOTION AND STRENGTHENING EXERCISES– FOR THE HAND AND WRIST

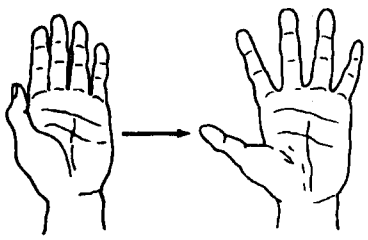
EXERCISE SHEET 9

These exercises can help bring back or maintain strength and range of motion of the hand. They are useful after **injuries** (or surgery) to the hand, after **broken arm bones** near the wrist ahve healed, and for **arthritis**, or partial **paralysis** from any cause (polio,spinal cord injury,stroke).

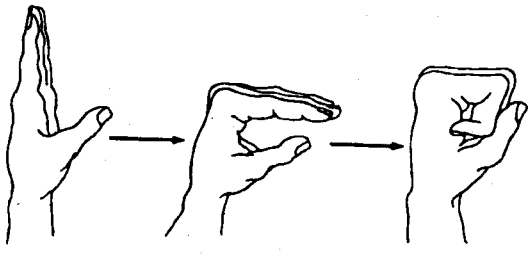
To do these exercises,the person should move the hand as much as possible without help. Then, if motion is not complete, use another hand to bend and straighten the fingers or wrist as much as possible without **forcing**.

Repeat each exercise 10 to 20 times ,at least 2 times every day.

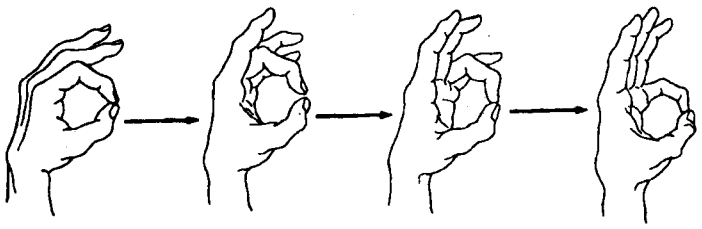
1. Close and spread the fingers as much as possible.



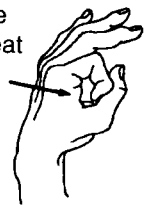
2. Open Bend like this Make a fist.



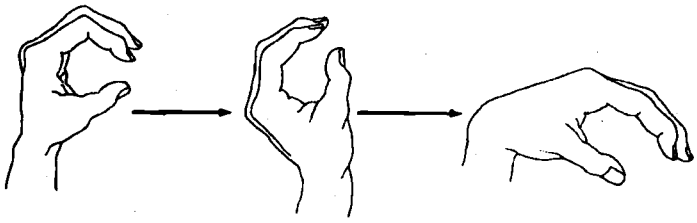
3. Make 'O's with the thumb and each finger.



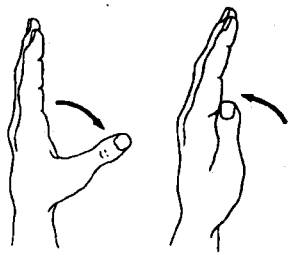
After you can make the large 'O's, repeat making the 'O' as small as you can.



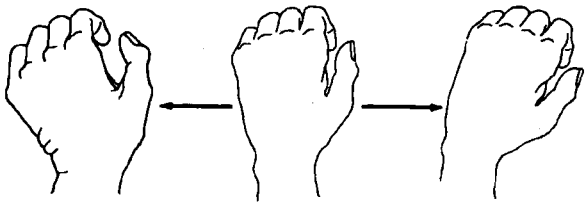
4. Bend wrist forward and backward. (Backward is more difficult but is especially important.



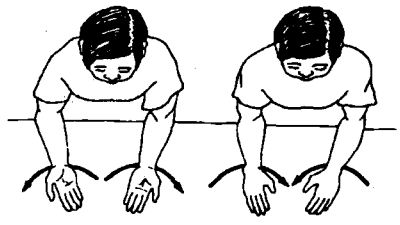
5. Spread and close the thumb



6. Bend the wrist from side to side.



7. Turn hands upward and downward–as far as you can.



MAKING HAND EXERCISES FUN OR USEFUL

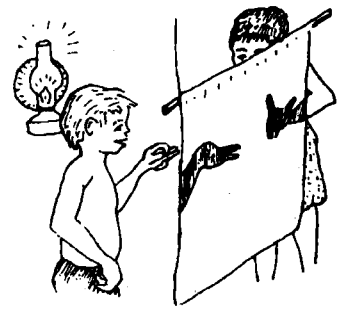
Look for ways to make hand exercises fun.

For example, try to learn sign language from a deaf child (see p. 320)





Or play 'shadow puppets' with a light



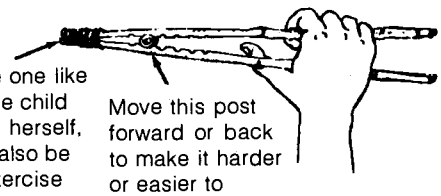
Aids for hand exercise

You can bu a simple hand exerciser lik this.





Or make one like this. If the child makes it herself, that will also be good exercise for her hands.

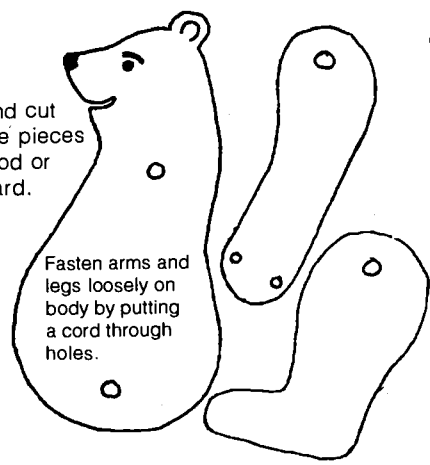


Move this post forward or back to make it harder or easier to squeeze the aid.

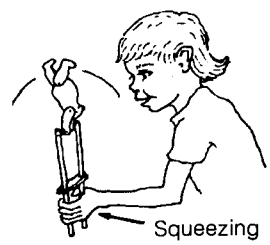
This **'acrobatic bear'** is more work to make, but even more fun to exercise and play with.



Trace and cut out these pieces from wood or cardboard.



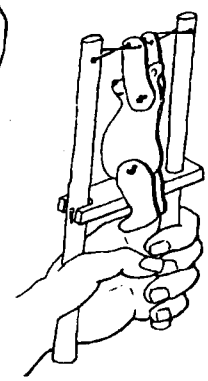
Fasten arms and legs loosely on body by putting a cord through holes.



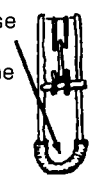
Squeezing the poles makes the bear 'loop the loop'.

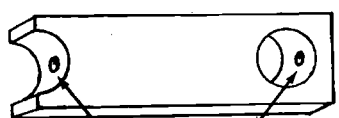


"See if you can make the bear sit.

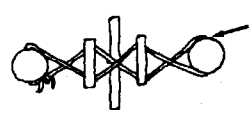


To have the child squeeze harder, attach a piece of rubber hose or car tire between the poles.





Pass a cord through holes in poles and in this piece.



view from above showing how string passes through holes in poles and paws.

A child can also get squeezing exercise with the hands by **milking goats, cutting with scissors or shears, punching holes in leather or paper** with a hand punch (while making things), by **washing and wringing clothes**, and in many other ways.

For examples of how different kind of exercises are used for different disabilities look under "Exercises' in the INDEX.

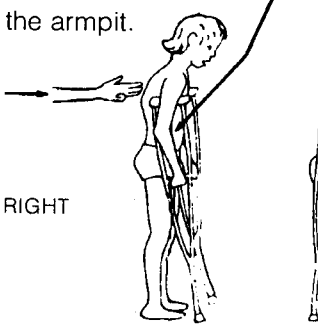
CHAPTER **44**

Crutch Use, Cane Use, and Wheelchair Transfers

USE OF CRUTCHES

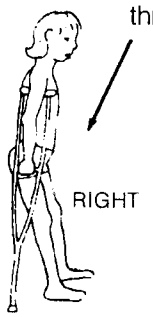
MAKING SURE THE CRUTCH FITS THE CHILD

When the child stands, the crutch should be 2 or 3 fingers' width below the armpit.



RIGHT

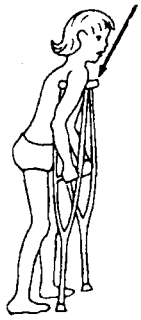
The elbow should be bent a little so that the child can lift herself up to swing her feet through.



RIGHT

IMPORTANT

Teach the child not to 'hang' on the crutches with her weight on her armpits.



WRONG

In time, pressure on the nerves under the arm can cause **paralysis** of the hands.



Using **elbow crutches** is a good way to keep her from hanging on her armpits. (However, these are more difficult to use for some children.)



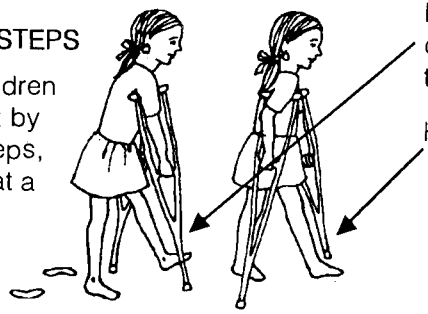
RIGHT

For designs and measurements of different crutches, see p. 708 to 711.

Walking with crutches

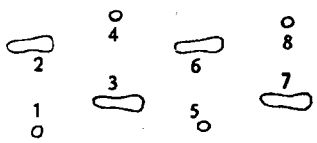
TAKING STEPS

Some children walk best by taking steps, one foot at a time.



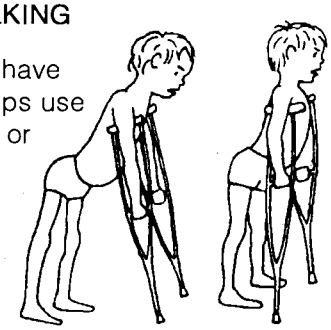
For better balance and position, move the right crutch forward together with the left leg, and then the left crutch together with the right leg.

Her 'tracks' should look like this.



' SWING ' TO WALKING

Many children who have difficulty taking steps use crutches by pulling or swinging both feet forward to the level of the crutch tips. Then they advance the crutches and pull themselves forward again.



This way is **slow but sure.**

SWING THROUGH ' WALKING'

Although at first they may be afraid to try it, many of these children can learn to 'swing through' between their crutches like this.



This way is **fast and fun.**

USE OF A CANE

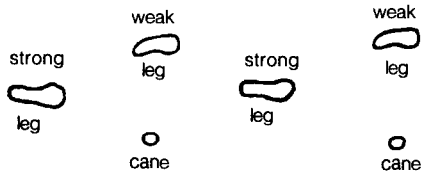
It usually works best to hold the cane on the side opposite the weaker leg.



Move forward and put down the weaker leg and the cane together.

For different crutch and cane designs, see chapter 64.

His 'tracks' should look like this.



WHEELCHAIR TRANSFERS

Persons who use wheelchairs become much more independent if they can learn to **transfer** (get in and out of their wheelchairs) by themselves, or with limited help. For those who need some help, it is important to find ways to transfer that make it easiest both for the disabled person and the helper.

Too often, as disabled children get bigger and heavier, mothers and fathers hurt their own backs.

Different persons will discover their own 'best way' to transfer with or without help, depending on their own combination of strengths and weaknesses.

Here we give some suggestions of ways to transfer that many people have found to work well.

THE WRONG WAY TO TRANSFER



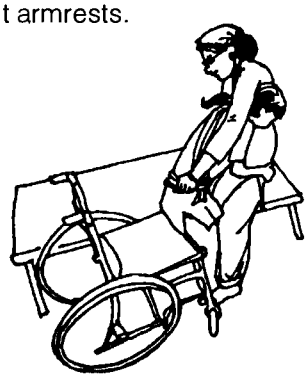
Warning
One disability can lead to another !

Notice that it is often easier to transfer sideways out of a chair,and also back into it. To transfer sideways, however, a **wheelchair without armrests,**or with at least one **removable armrest** is needed. Therefore, **for many disabled children, make an effort to get or make wheelchairs without armrests or with removable armrests.** Unfortunately, most wheelchairs in many countries have fixed, often very high, armrests. We therefore will give examples of transfers both with and without armrests.

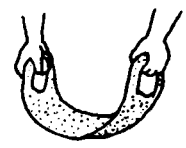
A good way to transfer the child who needs help is like this.

Put the child's feet on the floor and lean her forward against your body. Have her hold on as best as she can.

Lift her like this and swing her onto the bed.



To lift her, grip her pants or make a canvas or leather sling.

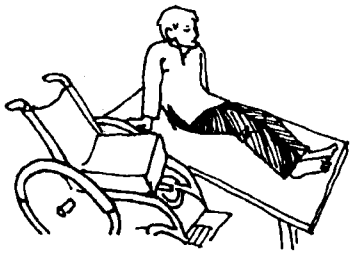


Ideas for wheelchair design, adaptation, and use are in Chapters 65, 66 and 67.

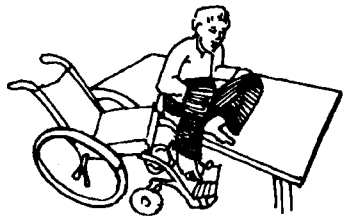
Transfer from cot or bed to wheelchair without armrests

> ***Caution :*** Make sure brakes are 'on' and footrests are 'up' out of the way.

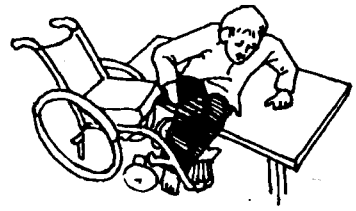
To transfer from the wheelchair to the cot, follow the same steps in reverse.



1. Push yourself to a sitting position.

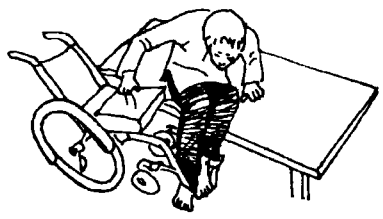


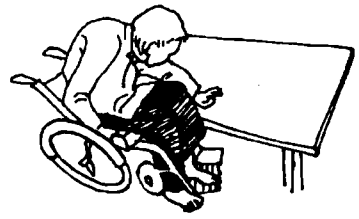
2. Reach under knees one at a time.



3. Move legs so that feet are on the floor.

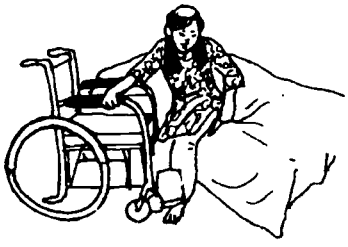
4. Make sure brakes are locked. Then push up on the arms while leaning forward with head facing down. Weight should be over the knees.



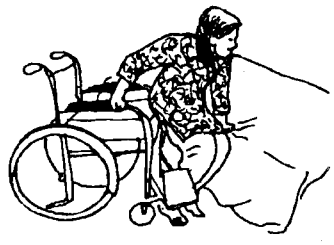


5. Move body into wheelchair.

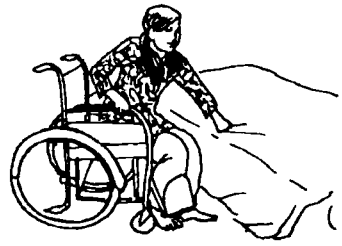
Transfer from cot or bed to wheelchair with armrests



1. Position your wheelchair so that you can swing body past armrests.

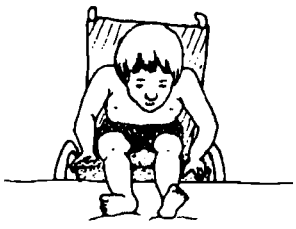


2. Place one hand on bed and one on the far armrest. Push yourself up while leaning forward with head down, weight over knees.

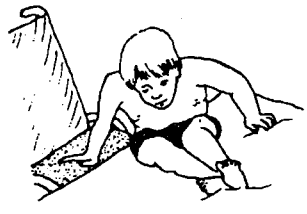


3. Swing body into wheelchair.

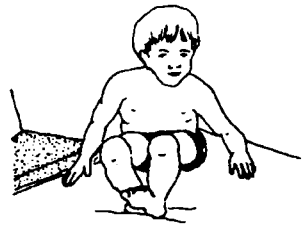
Transfer forward from wheelchair to cot or bed (often works well for children)



1. Lift feet onto bed and wheel the chair forward against bed. Put on brakes. Then bend forward and lift buttom forward on chair.



2. With one hand on the cushion and one on the bed, lift the body sideways onto the bed.



3. Repeated lifts and lifting of legs may be needed.

Transfer with sliding board – without help

For getting into and out of bed, a car, etc.

SLIDING BOARD

about 23 cm. (10 inches)

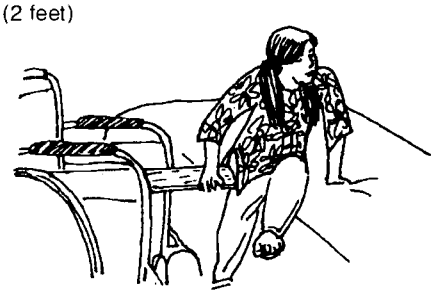


round ends

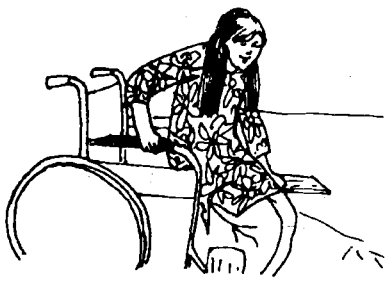
about 65 cm. (2 feet)



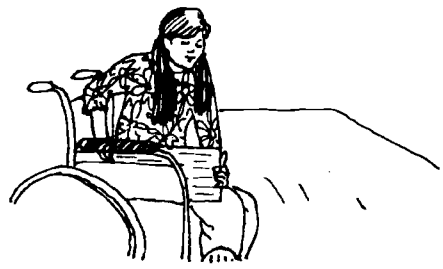
1. Place board under hip by leaning to opposite side or by pulling up leg.



2. Lean forward, with your head and weight over knees.

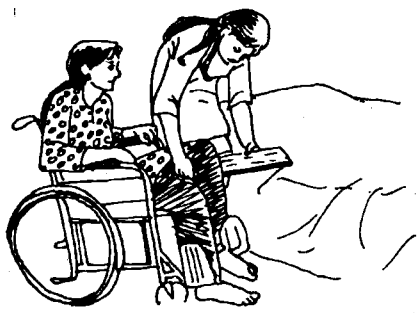


3. Push yourself forward along the board.



4. When you are in the chair, remove the board and put it where you can easily get it.

Transfer with sliding board – with help



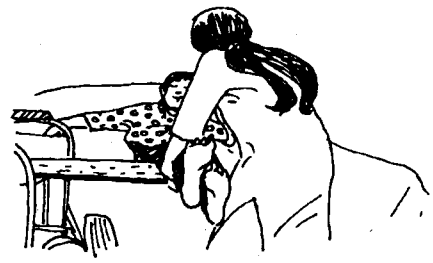
1. Lift leg and put board under hip.



2. Have person put arms around neck (if possible) while you put your hands under his buttom, or grab her pants.

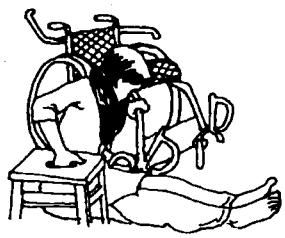


3. Slide the person along board to bed.



4. Lift legs onto bed.

Transfer from floor to wheelchair – with help of a low seat



1. Sit with legs straight. Pull seat to your side opposite the wheelchair (a person's knee can also be used).



2. With hands on each chair, push up, with your head forward over knees.



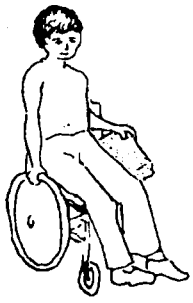
3. Swing onto the seat.



4. Now, with your head forward over your knees, swing body onto the wheelchair.

Transfer from wheelchair to floor – and back again – without help of a stool

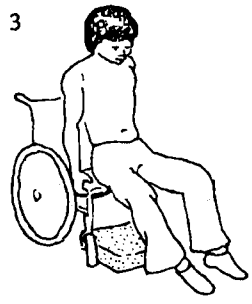
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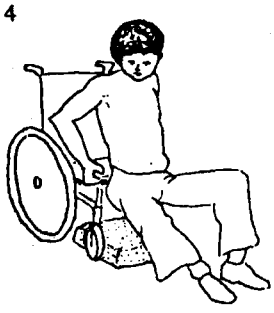
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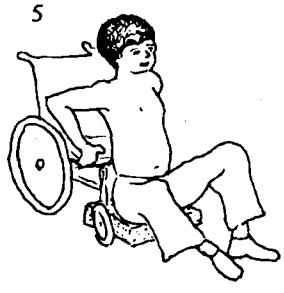
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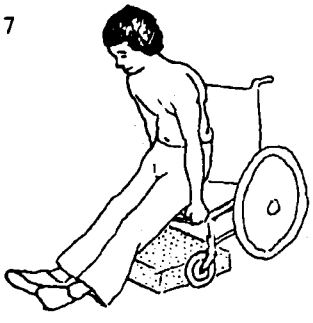
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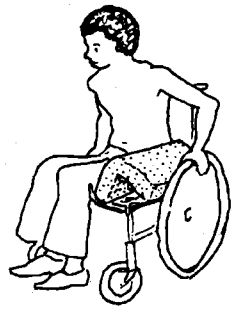
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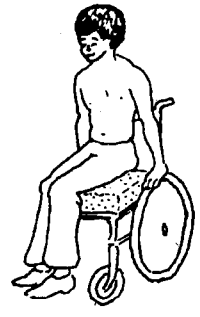
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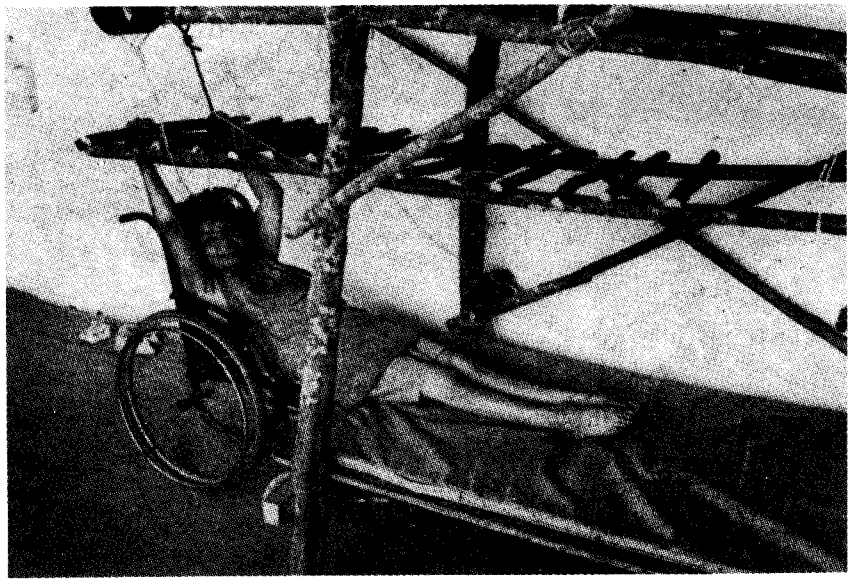


9









This woman, who has severe spasticity, transfers from wheelchair to bed using tin cans, ropes, and a wood frame over her bed. (Photo : John Fago, PROJIMO.)

PART 2

WORKING WITH THE COMMUNITY

Village Involvement in the Rehabilitation, Social Integration, and Rights of Disabled Children





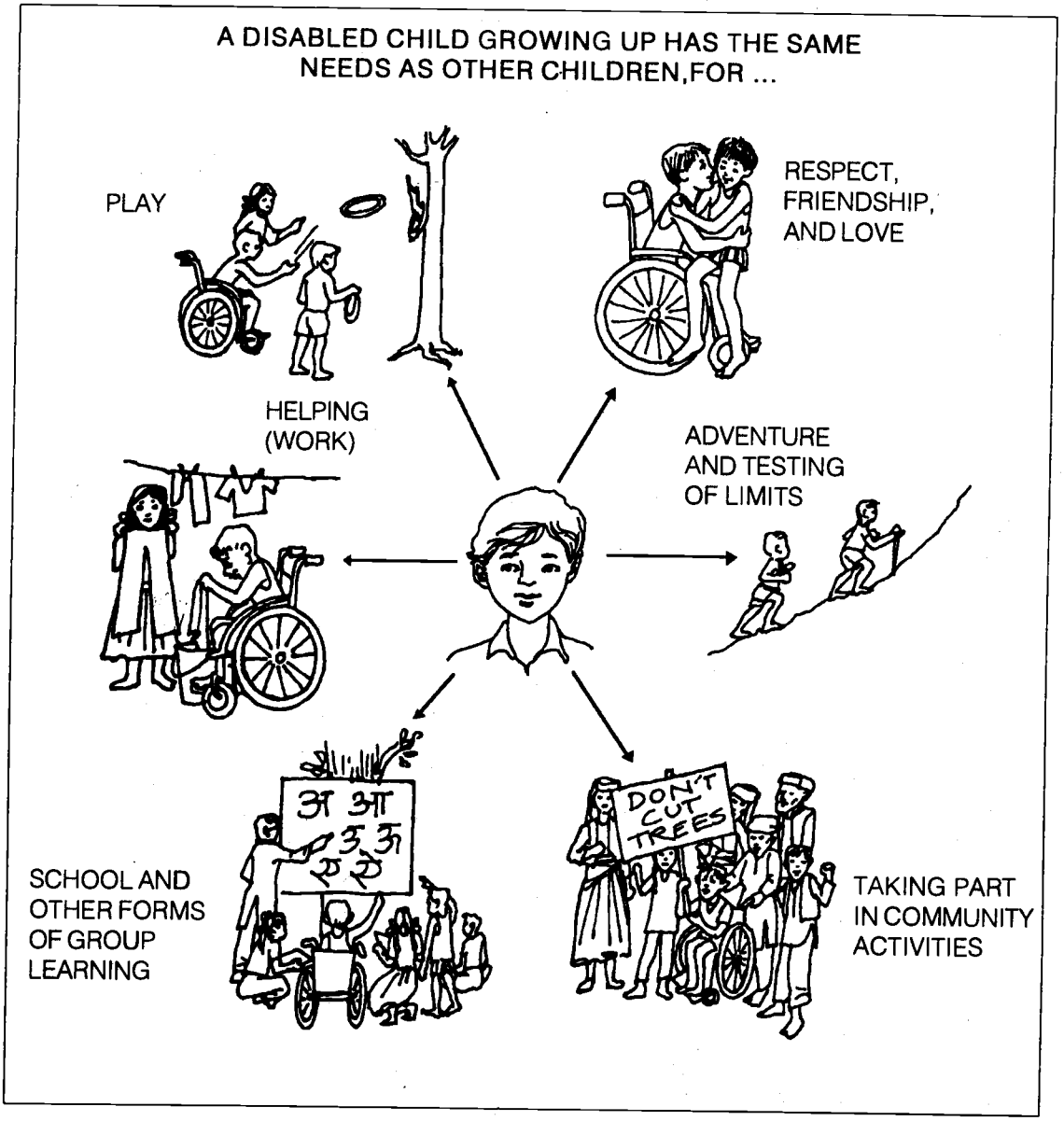
INTRODUCTION TO PART 2

CHAPTER 45

Disabled Children in the Community

In PART 1 of this book, we discussed ways of working with individual children according to their particular disabilities. However, a lot of what can make life better – or more difficult – for a child comes not from the child's disability itself, but from the way that people in the family and community look at and treat the child.

In this part of the book (PART 2) we look at ways to actively involve members of the community – disabled persons, their families, concerned adults, schoolchildren, and others – in meeting the needs of disabled children and in helping them find a meaningful place in the community.



In every society, disabled children have the same social needs as other children. They need to be loved and respected. They need to play and explore their world with other children and adults. They need opportunities to develop and use their bodies and minds to their fullest ability, whatever that may be. They need to feel welcome and appreciated by their family and in their community.

Unfortunately, in most villages and neighborhoods, disabled persons – including children-are not given the full chance they deserve. Too often people see in them only **what is wrong** or different without appreciating **what is right.**

DIFFERENT COMMUNITIES REQUIRE DIFFERENT APPROACHES

The way people treat disabled persons differs from family to family, community to community, and country to country.

- **Local beliefs and customs** sometimes cause people to look down on disabled persons. For example, in some places, people believe that children are born disabled or deformed because their parents did something bad, or displeased the gods. Or they may believe that a child was born defective to pay for her sins in an earlier life. In such cases, parents may feel that to correct a deformity or to limit the child's suffering would be to go against the will of the gods.
- **Lack of correct information** often leads to misunderstanding. For example, some people think that ***paralysis*** caused by polio or cerebral palsy is 'catching'(contagious), so they refuse to let their children go near a paralyzed child. Often people think that a child with mental retardation is mad' so they do not let their children either play or study with them or they think that mental retardation is an infectious disease.
- In many societies, children who have fits or ***mental*** illness are said to be possessed by the devil or evil spirits. Such children may be feared, locked up, or beaten.
- **Failure to recognize the value and possibilities of disabled persons** may lead to their being neglected or abandoned. In many countries, parents give their disabled children to their grandparents to bring up. (In return, many of these children when they grow up take devoted care of their aging grandparents.)
- **Fear of what is strange, different, or not understood** explains a lot of people's negative feelings. For example, in communities where polio is common, a child who limps may be well accepted. However, in a community where few children have physical disabilities (or where most who do are kept hidden), the child with a limp may be teased cruelly or avoided by other children.
- **How severe a disability** often influences whether or not the family or community gives the child a fair chance. In some parts of Africa and India children with polio who manage to walk, even with braces or crutches, have a good chance of becoming well accepted into society. The opposite is true for children who never manage to walk. Even though most could learn important skills with their hands and perhaps become self-sufficient, the majority of non-walkers die in childhood, largely from hunger or neglect. Mentally handicapped persons are better accepted in rural India than in urban areas. The expectations of urban parents are usually high as they try to meet the standards of the community in which they live.
- **Where poverty is extreme**, a child's disability may seem of small importance. Often when families are asked about their disabled child, the mother says her biggest worry was that of food and a roof over their heads. Rehabilitation workers may need to help organise these basics first.Only when the basic needs of food and shelter were met, could the mother give attention to her child's disability.



(Photo: Philip Kgosana, UNICEF, Sri Lanka.)

Overprotection

Certainly not all disabled children are neglected or treated cruelly. A disabled child is often treated by the family with an enormous amount of love and concern . It is common for parents to spend their last rupee trying to cure their child or to buy her vitamins or sweets, even at the cost of hardship for the other children.

Providing too much protection is one of the biggest problems. The family does almost everything for the child, and so holds her back from developing skills and learning to care for herself. Even a child with a fairly ***mild disability*** is often not allowed to play with other children or go to school because her parents fear she will be teased, or unable to do as well as the others.



Even , where families provide loving care for their disabled children, **they often keep them hidden away.** Seldom do you see a child playing in the streets, helping in the marketplace or working in the fields. Partly because disabled persons are given so little chance to take part in the life of the community, everyone assumes that they cannot- and should not. Disabled children often grow up as outsiders in their own village or neighborhood. They are unable to work, unable to marry and have children, unable even to move about and relate freely to others in the community. This is not because their disabilities prevent them, but because society makes it so difficult.

Yet things do not have to be like this. A few years ago in India, people in the community did not know about polio. They would stare at, turn their backs on, or express their sorrow for these children, thinking it was the wrath of god that had led to this condition. As a result; parents hardly ever took their children to rehabilitation centres and the children often ended up on their hands and knees.

But now, as a result of intensive campaigns, more and more people are realising that the causes of polio are really man made conditions and lack of immunisation. Many more parents are aware of the symptoms of polio and are taking their children to rehabilitation centres as soon as they get it. Disabled children and their parents are more comfortable about being seen in public.



In Ajoya, Mexico non-disabled and disabled children play together in a 'playground for all' built by the village children with their parents' help. The community has helped build special paths and ramps so wheelchair riders can get to the stores to the village square, in and out of some homes, and to the outdoor movie on Saturday nights.

As awareness grows, the community also becomes motivated. In village Tigaon in Haryana, the village first gave space in a temple for a rehabilitation centre run by the spastics society of Northern India. Later, they gave them land. The society now runs a full fledged rehabilitation centre for children with polio and cerebral palsy.

In places where, groups of parents of disabled children have got together to form associations or self help groups, other disabled children are coming out of their houses to join them.



PHOTO : SEWA —IN— ACTION

In PART 2 of this book we look at ways to help the community respond more favorably to disabled children and their needs. Usually, of course, a village or neighborhood does not decide, on its own account, to offer greater assistance, acceptance , and opportunity to disabled persons and their families. Rather,**disabled persons and their families must begin to work together, to look for resources, and to re-educate both themselves and their community.** Finally-when they gain enough popular understanding and support-they can **insist on their rights**.

The different chapters in PART 2 discuss various approaches and possibilities for bringing about greater understanding of the needs and possibilities of disabled children in their communities. We start by looking at what disabled persons and their families can do for themselves and each other. We look at possibilities for starting a **family-based rehabilitation program,** and the importance of starting **community-directed rehabilitation centers.** We explore ways to include village families and school children. Finally, we look at specific needs of the disabled child growing up within the community-needs for group play, schooling, friendships, respect, self-reliance, social activities, ways to earn a living or to serve others; also needs for love , marriage, and family.

EXAMPLES, NOT ADVICE

In this part of the book, which deals with community issues, we will try mostly to give examples rather than advice. When it comes to questions of attitudes, customs, and social processes, advice from any outsider to a particular community or culture can be dangerous. So as you read the experiences and examples given in these pages, do not take them as instructions for action. Use, adapt, or reject them according to the reality of the people, culture, needs, and possibilities within your own village or community.

Each community is unique and has its own obstacles and possibilities.

CHAPTER **46**

Starting Village-Based Rehabilitation Activities

TOP-DOWN OR BOTTOM-UP?

Around the world today there are many examples of what have sometimes been called 'community-based rehabilitation programs'. Some of these programs are 'top down'; others are 'bottom up'.

Top-down: Chain of command

Top-down programs or activities are mostly planned, started, organized, and controlled from outside the community: by government, by an international organization, or by distant 'experts'. And the local leaders are usually persons in positions of authority, influence, or power.



Bottom-up: Equality in decision-making



Bottom-up programs or activities are those that are largely started, planned, organized, and controlled locally by members of the community. Much of the leadership and direction comes from those who need and benefit most from the programs's activities. In brief, the program is **small, local,** and **'user-organized'.**

Community participation is important to both top-down and bottom-up programs. But it means something different to each:

In top-down programs, people are asked to participate only in ways that have already been decided from above. For example, a decision might be made by a team of foreign specialists that certain persons in each community be selected as 'local supervisors'. The local supervisors are taught several pre-decided 'packages' of cookbook-like information. Each supervisor then instructs a given number of 'local trainers' (family members of the disabled) how they 'must train' each particular disabled person. Thus 'community participation', from the viewpoint of the experts, means 'getting people to do what we decide is good for them'.

In bottom-up programs, 'community participation' means something else. The program develops within a village or neighborhood, according to the needs and wishes of its members. It may take an outsider with some knowledge in rehabilitation and skill in organizing people to help get things started. But it is the people themselves, especially disabled persons and their families, who make the decisions about their own program. They can learn from other programs and from the experts. But they do not simply copy or follow others. They pick and choose from whatever advice and information they can get in order to plan activities that fit the needs and possibilities of their particular village, and their particular children.



In the village of Ajoya, Mexico, over 60 families participated in building a cement walkway from the rehabilitation center to the main street.

There are advantages and disadvantages to top-down and bottom-up. For a central government, a standardized, top-down approach is easier to introduce, administer, and ***evaluate*** in many communities at the same time. But in primary health care, it has become clear that top-down programs frequently fail or have serious weaknesses, mainly because they do not have enough popular leadership, understanding, and personal commitment. These are especially important for rehabilitation. Every disabled child is different and has her unique combination of needs. An imaginative, problem-solving approach is essential. If decisions and plans come pre-packaged from above, rehabilitation measures often do limited good and sometimes even harm.

In a bottom-up approach there is a greater sense of equality, and of arriving at decisions together. People do not just follow instructions. They consider suggestions. They want to know ***why***. This greatly increases the chances that exercises, aids, and activities will really fit the individual needs of the child. It also makes rehabilitation more interesting, meaningful, and valuable for all concerned. It helps both parents and children become more independent.

In a bottom-up approach to rehabilitation has the advantage of flexibility and adaptability that comes from being organized and controlled locally. **Planning is a continuous learning process** that responds to the changing needs, difficulties, and possibilities within the community. Expecially when disabled persons and family members play a leading role, participants at every level are likely to develop a spirit of respect, friendliness, and equality that keeps a program human and worthwhile.

Above all, a bottom-up program organized by those it serves, decentralizes and redistributes power: people who have been powerless begin to find strength through unity. You can never be sure where things may lead, how far people may go in terms of taking charge of their own lives or in demanding their rights.



On the following pages we look at community rehabilitation activities and programs from a 'bottom-up' approach in a village situation. This is where our own experience lies. For a different approach with more of the planning from above we suggest you see the World Health Organization's ***Training Disabled Person In the Community*** along with the supplementary materials (see p. 769). For a sharp analysis of different approaches. read Mike Miles' ***Where There Is No Rehab Plan*** (see p. 733).

STARTING IN A VILLAGE-WHERE TO BEGIN?

Rehabilitation of disabled persons within a village or neighborhood usually has two major goals:

1. To create a situation that allows each disabled person to live as fulfilling, self-reliant, and whole a life as possible, in close relation with other people.

2. To help other people-family, neighbours, school children, members of the community-to accept, respect, feel comfortable with, assist (only where necessary), welcome into their lives, provide equal opportunities for, and appreciate the abilities and possibilities of disabled people.

One of he best ways to bring about better understanding and acceptance of disabled people is to involve both disabled and non-disabled persons in shared activities. The next few chapters discuss selected community activities that can help improve people's understanding and respect for the disabled. These can be introduced either as part of a rehabilitation program, or independently by concerned persons such as parents, school teachers, or religious leaders. Some of these activities, in fact, have proved to be good ways to create interest and open discussion with local people about starting a small community-based program.

There are many possibilities for getting people in a village or neighborhood more actively involved. Often a good way to start is to **call a meeting to bring together disabled persons and family members of the disabled.** Sometimes one or more leaders in the community happen to have a child or close relative who is disabled. These persons, with a little encouragement, may take the lead in organizing other families with disabled children, or in starting a local rehabilitation program.

It makes sense to **start where people express their biggest concern.** For example, in Peshawar, Pakistan, a community program for ***retarded*** children was started because families of these children expressed a strong need. In Nicaragua, a group of disabled revolutionaries with ***spinal cord injuries*** started a program to produce low-cost wheelchairs to meet their particular needs. In Mexico, ***physically disabled*** village health workers started a community program for disabled children and their families. Today, these 3 programs have all expanded their coverage to include a far wider range of disabilities than they started with.

Some children have several disabilities, so it is hard to limit attention only to certain ones. We must try to meet the needs of the whole child, within the family and within the community. However, it often works best to start in a **small and fairly limited way, wherever people are ready.** Let things grow and branch out from there, as new concerns arise and new people become involved.



In a community program everyone helps out. Here the mother of a boy with polio sews cloth to form 'stockings' for use under plaster casts.

Who gets things started?

Within a community or neighborhood there will often be persons eager to become involved in starting rehabilitation activities or even a program. All it may take is something to 'spark the idea'. This spark can be in the form of a person, a pamphlet, or even a radio program that triggers people's imaginations with ideas or basic information.

For example, we know of one village medic, herself disabled by polio, who received a WHO magazine with an article on "Rehabilitation of All." As a result, she began to organize the villagers to build a simple rehabilitation playground. In a similar fashion, CHILD-to-child activity sheets have sometimes inspired teachers to conduct activities that help school children to prevent certain disabilities or to behave toward disabled children in a more friendly, welcoming way.

Often, to get things started, it takes a person with some background in rehabilitation and in community work, to stay for a while in a village or neighborhood. Her role is to bring together people with similar needs, helping them to form a plan of action and to obtain the information and special resources they need.

Such a 'resource person' is sometimes called an '**agent of change**'. She need not be a highly-trained professional in rehabilitation or social work. In fact, persons who have professional degrees often have the hardest time accepting the parents and disabled persons can and should be the primary workers and decision makers in a community rehabilitation program.

What is necessary is that the agent of change be someone who respects ordinary people, and is committed to helping them join together to meet their needs and defend their rights.

The agent of change should be a counselor, not a boss; a provider of information and choices, not orders or decisions. Especially when such a person comes from outside the community, her role is to stay in the background, to help the people make their own decisions and run their own program. At all costs she avoids taking charge.

Staying in the background, however, is easier said than done, especially for an agent of change who is deeply committed. To make sure that a program is run by the people, not by outsiders, it is often a good idea that agents of change and any visiting professionals not be present all the time. Instead, they should encourage the program to continue without them. Perhaps the final test of an agent of change's success is to leave the community forever, without her absence being much noticed. These ideas are said beautifully in this old Chinese verse:

Go in search of Your People:
Love Them;
Learn from Them;
Plan with Them;
Serve Them;
Begin with what They have;
Build on what They know.



But of the best leaders
when their task is
accomplished,
their work is done,
The People all remark:
"We have done it Ourselves."

To help start a program for the disabled, it often works out better if the agent of change is also disabled. This helps make the *outsider* an *insider*.

Disabled persons as leaders and workers in rehabilitation activities

Some of the most exciting and meaningful community rehabilitation activities in various parts of the world are those that are **led and staffed by disabled persons themselves.** When the leaders and workers in a program are disabled, they can be excellent role models for disabled children and their parents. When they see a team of disabled persons working together productively, doing more to help other people than most able-bodied persons do, and enjoying themselves in the process, it often gives both family and child a new vision and hope for the future. This alone is a big first step toward rehabilitation.

Another reason for recruiting leaders and workers who are mostly disabled persons (or their relatives) is that they are more likely to work with commitment, to give of themselves. From their own experience they understand the problems, needs and possibilities of disabled persons. Because they, too, have often suffered rejection, misunderstanding, and unfair treatment by society, they are more likely to become leaders in the struggle for a fairer, more fully human community. Their weakness contributes to their strength.



Disabled workers give an example to disabled children that they can lead a helpful, full life. Polo Leyva, severely disabled by polio, has become a skilled welder and wheelchair maker.

Examples of community rehabilitation programs run by local disabled person are in Chapter 56.

Kinds and levels of village-based activities

There is no formula or blueprint for starting a village rehabilitation program. How things get started will depend on various factors: the size of the village, the number and nature of disabled children, the interests and talents parents and other persons, the resources available, the distance and difficulties for getting specific rehabilitation services elsewhere. Also consider the possibilities for getting assistance (Voluntary, if possible) from ***physical therapists*** and other rehabilitation professionals, craftspersons, health workers, school teachers,
counsellors and others with skills that could be helpful.

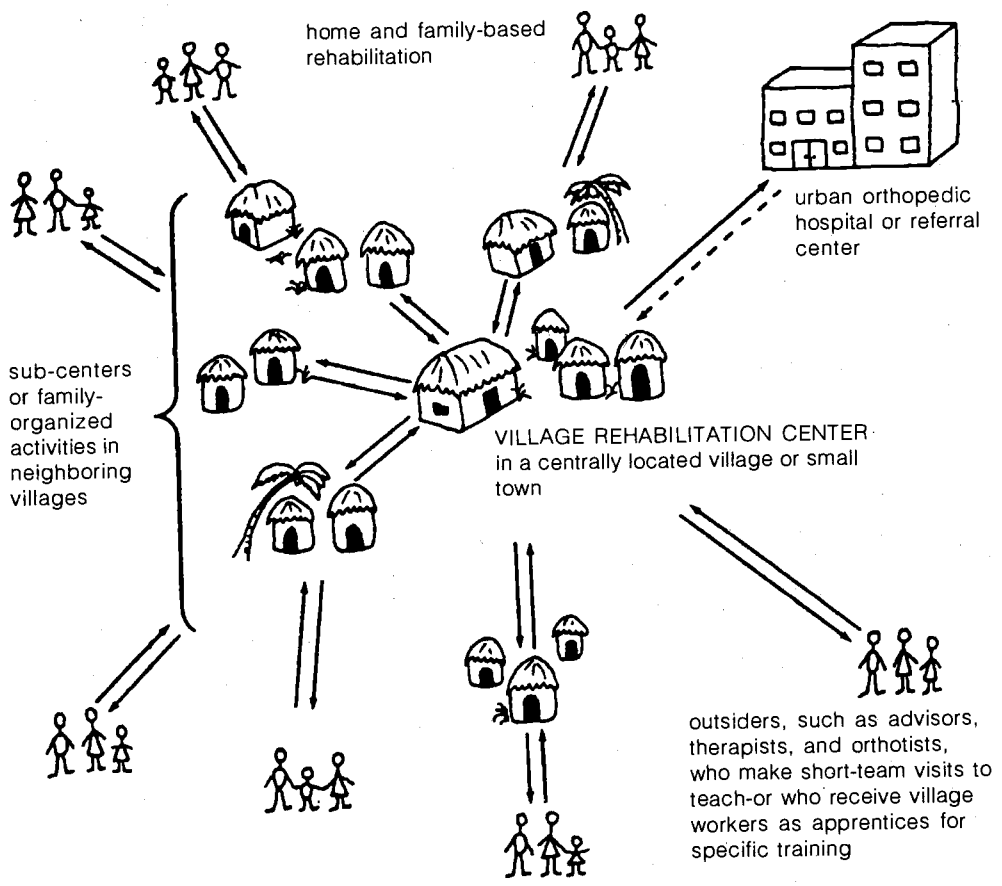
If rehabilitation is ever to reach most of the children who need it, **most rehabilitation activities must take place in the home** with the family members as the primary rehabilitation workers. And even where plenty of money and professional services are available, the home and community are still the most appropriate place for most of the rehabilitation of most disabled children.

For home-based rehabilitation to be effective, however, parents need carefully prepared and selected information, friendly encouragement, and assistance. And at times they will need back-up services of rehabilitation and medical workers with different kinds and amounts of skills.

A good arrangement, perhaps, is a **referral chain**, starting with rehabilitation in the home with guidance from a small community center run by local, modestly trained workers. If possible, the center has close links with the nearest low-cost or free ***orthopedic*** hospital and professionally-run rehabilitation center, to which the relatively few children with disabilities requiring surgery or complex ***therapy*** can be referred. Outside professionals (***orthotists, therapists,*** and others) can help by making periodic teaching visits to village rehabilitation centers. They can also invite village workers to visit and apprentice with them in their city shops and clinics. (***Apprentice*** means to learn by helping someone more skilled.)

Some villages will be too small or lack the resources to start their own community rehabilitation center. However, it has been found in several countries that once a modest center in one village opens, the word spreads. Disabled children with family members soon begin arriving from surrounding villages. In time the rehabilitation team may be able to help disabled persons and their families in neighboring village to organize their own sub-centers. Disabled workers from these sub-centers can learn by 'apprenticing' at the original center.

OUTREACH AND SUPPORT SYSTEM FOR A VILLAGE REHABILITATION CENTER



The above 'ideal' is more or less the way Project PROJIMO in Mexico works, although with certain difficulties and obstacles.

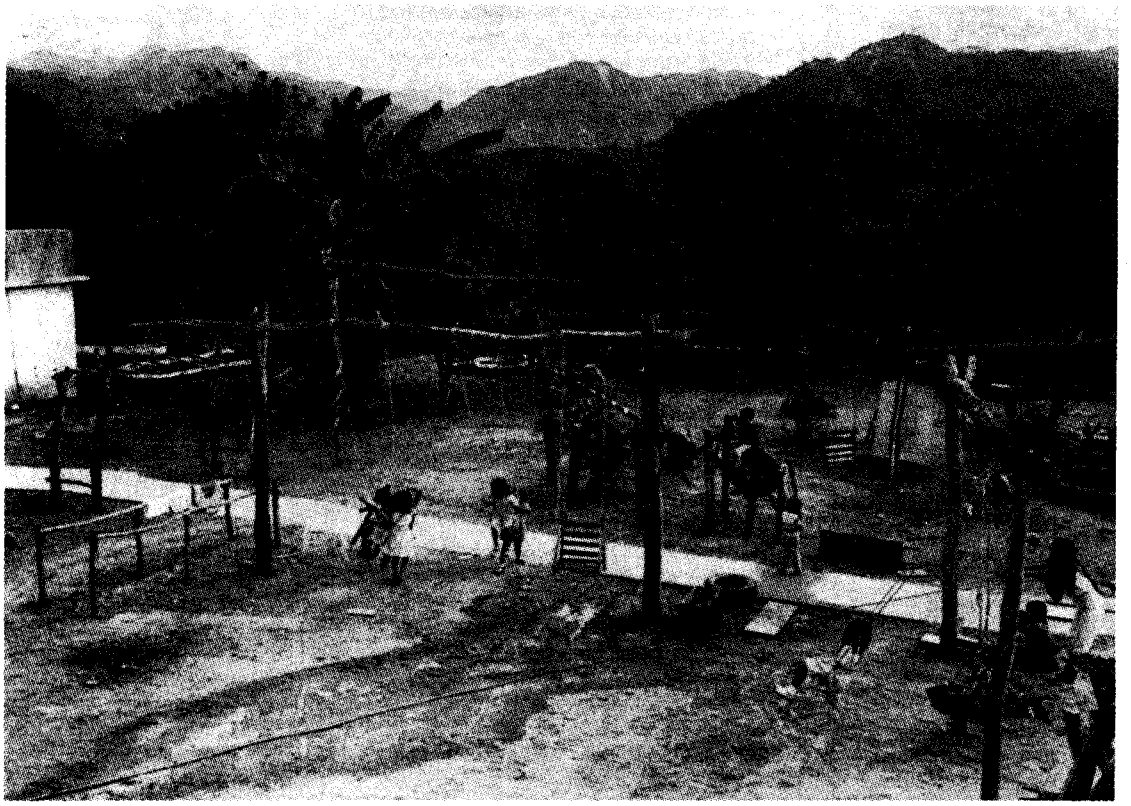
The role of a villager-run rehabilitation center

Some of the most important rehabilitation activities take place with the family in the home. Others take place in the school, the marketplace, the village square, and when necessary, in the nearest orthopedic hospital. **They key to helping all this happen can be the village rehabilitation center.** (see the next page.)

A village rehabilitation center run by modestly trained disabled workers, together with the families of disabled children, can provide a wide range of services. These may include training and support of families, community activities, non-surgical orthopedic procedures, and making orthopedic and rehabilitation aids. The program need not try to do everything at first, but can start with what seems most important and gradually add new skills and activities as needs and opportunities arise.

Eventually, a community team can gain considerable skill in many areas. For example, the village team of PROJIMO is able to adequately attend the needs of about 90% of the disabled children it sees (except for blind or deaf children for whom its services are still not adequate). Only about 10% need referral to orthopedic hospitals or larger rehabilitation centers. Visiting experts have found that at times the therapy or aids provided by PROJIMO are more helpful than those previously provided to the same children by professionals in the cities.

The chart on the following page gives an idea of possible activities and functions of a village rehabilitation center. It also lists activities of possible 'sub-centers' in neighboring villages, as well as referral and support services needed from urban orthopedic and rehabilitation centers, and outside specialists.



Organizing the community to build a 'playground for all children' is one of the best ways to increase participation and to integrate disabled and non-disabled children in a way that everyone enjoys.

POSSIBLE ACTIVITIES AND FUNCTIONS OF REHABILITATION CENTER AT DIFFERENT LEVELS

Sub-centers in neighboring villages



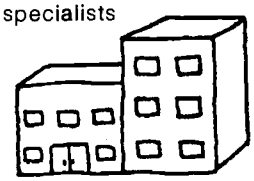
- parent meetings mutual assistance and shared child care between families of disabled
- playground for all children (disabled and non-disabled)
- group action to get disabled children into school
- special group activities for children who cannot attend normal school
- community awareness raising activities:
  - skits
  - CHILD-to-child
  - involving school children and villagers in building play-ground, improving accessibility, making toys and equipment
- organized (group) visits to the village rehabilitation center in the neighboring village
- educational and preventive activities
- perhaps one or more 'village rehabilitation assistants' to help with basic therapy and rehabilitation, under guidance from rehabilitation workers from the village rehabilitation center

VILLAGE REHABILITATION CENTER

(serving children and their families from a group of villages)

- all of the activities listed for the sub-centers. And also:
- family and small group training in basic care, therapy, and development of disabled children (guidelines and advice)
- workshop for making and repairing (and teaching families how to make and repair) orthopedic and rehabilitation aids including
  - braces - wheelchairs - crutches - artificial limbs - walkers - special footwear - special seating - therapy aids
- non-surgical orthopedic procedures (straightening joints with series of casts. etc.)
- arrangements within village to provide room and board for visiting disabled children and family members from neighboring villages
  This may include :
  - village families who are willing to take in visiting families at low cost
  - a 'model home' where visiting families can stay, equipped with low-cost adaptations and equipment for better function and self-care by the disabled
  - coordination, informal training, visits and advice to parent groups or sub-programs in neighboring villages
- workshops and/or agricultural projects where disabled youth can learn income-producing skills to bring in some income to the program or family
- prevention campaigns, for example
  - vaccination against polio and childhood diseases, with special focus on underserved families and communities
  - education campaign against over use and misuse of injections
- activities to involve and include as much of the community as possible (adults and children) in the program, possibly,
  - help with therapy
  - help with play and entertainment
  - accompany disabled children on outings. help them get to school, etc.
  - village support committee
  - a toy-making workshop where village children make toys for disabled children and also for their little brothers and sisters
- outreach to help start neighboring sub centers, with provision of training, back up referral services, and regular visits

Urban orthopedic and rehabilitation referral centers, and outside specialists



- referral services for: orthopedic evaluation, advice and surgery as needed (at low or no cost)
- orthopedic and rehabilitation equipment too complicated to be made at village level
- periodic visits by orthopedic surgeons to village rehabilitation center to evaluate possible surgical needs of selected children
- **short teaching visits** (3 days to 1 month) by visiting specialist (physical therapists, occupational therapists, special teachers, limb makers, rehabilitation engineers, etc.) to **teach and advise the village team** (It is important that such visitors play a secondary, background role and not be present all the time, nor take charge or work independently with children)
- **apprenticeship opportunities:** learning for village. workers in the centers of the different specialists

The importance of community-run rehabilitation centers

In an attempt to get the focus of rehabilitation out of big institutions and into the home, some community-based rehabilitation programs have tried to manage without any kind of local rehabilitation centers. "Local supervisors' make home visits and work directly with the families of the disabled. However, when additional assistance or aids are needed, the local supervisor often has nowhere to turn. She has to send the disabled person to professionals in the city. For reasons of distance, cost, fear, or failure of the support system, these referrals too often do not work out. As a result, rehabilitation is often incomplete, and people get discouraged.

Of course, referral to large city hospitals or centers will still be important for selected individuals. however, there are several **strong arguments in favor of setting up a small village or community-based rehabilitation center run by local concerned persons:**

1. It is a visible, practical, low-cost base for coordinating rehabilitation activities in the home, and for providing back-up services outside the home.

2. It can produce a wide range of rehabilitation equipment and aids quickly and cheaply, using local resources, with participation of families, schoolchildren, and local craftspersons, when possible.

3. It can include a 'playground for all children' and organize activities to encourage understanding and interaction with the disabled.

4. It can provide meaningful work and training experience for local, otherwise often untrained and unemployed disabled persons. It gives the families of disabled children and other villagers the chance to see what a useful, helpful, and rewarding role disabled persons can have in a community.

5. Although the best place for day-to-day rehabilitation is often the home, there are families for whom this may be very difficult. These include families in which one or both parents have left or are dead, or have drinking problems, or where step parents or other family members are cruel to the child, neglect her, or abuse her sexually (a fairly common problems). In many homes, the family does the best it can. But the extra work of trying to care for a ***severely disabled*** child may simply be too much for the family that has to work long hours just to survive. Under any of these circumstances, special care at a community center may be of enormous benefit to both the child and the family.

6. If many small community centers join to form a 'network', they can exchange ideas and learn from each other. Or different centers can 'specialize' in producing different supplies or equipment. For example, one village center might make wheelchairs, another toys, and another low-cost plaster bandage for casting. Then different centers or programs can supply each other at low cost.

Home-based rehabilitation often works much better with the help of a local community-run center.

How small, local programs spread to new villages and areas

Bottom-up programs tend to spread through popular demand. As the news of the program travels from family to family and town to town, even a small program based in a single village can reach far in its impact. For example, Project PROJIMO is based in a village of less than 1000 and has a staff of a dozen disabled villagers. In its, first 4 years, PROJIMO has attended to the needs of over 1,000 disabled children from over 100 town and villages and the slums of several large cities. (Since roughly one child in every 100 people is moderately to severely disabled, PROJIMO is in effect serving a population of over 100,000.)

There are various ways that bottom-up or 'people-centered' programs tend to spread. We speak of their growth as 'organic because they grow and spread in a living, whole sort of way, like seeds into trees.

In Project PROJIMO, some of the young people from neighboring communities, who first come for rehabilitation, decide to stay and to work for a while in the program. In the process they learn skills which they can use to help in the rehabilitation of other persons when they return to their own communities. In some cases,other villages and village-based health programs have sent young disabled persons to apprentice with PROJIMO for several months, in order to help start similar activities on return to their communities.

Another people-centered program that started small and has spread to many other towns is the Community Rehabilitation Development Program in Peshawar, Pakistan. This is discussed on p. 625.

ACTIVITIES IN THE COMMUNITY TO WIN INTEREST AND UNDERSTANDING

Group activities in a village or neighborhood can help improve understanding of and interaction with the disabled children. Four types of activities that have proved especially useful are discussed in the next 4 chapters:

- **A 'Playground for all children'.**
- **CHILD-to-child activities**
- **Popular theater**
- **A children's workshop for making toys**

Any of these activities may be used to gain people's interest and involvement when starting a community rehabilitation program. Or they can be used to increase understanding even where no special program is planned. For example, the workers in a village with a rehabilitation center can visit neighboring villages and put on skits or puppet shows about disability prevention.



Playground for all children-PROJIMO

They might also talk with school teachers, local health workers or concerned parents about developing CHILD-to-child activities, or organize local children to build a 'playground for all children'. Project PROJIMO took a truckload of school children to a neighboring village to help the children there build their own playground. Nearly 100 children and adults built the playground in one day.

After these 4 chapters, we will explore other aspects of social integration and opportunities for the disabled.

COUNSELLING

Parent /Family Counselling

Counselling forms an important aspect of the rehabilitation program. While dealing with children with disabilities it is also necessary to recognize the needs of their parents so that appropriate resources are created to help them cope with these needs.

What is this need ? When parents find out for the first time that their child is disabled they feel a tremendous sense of loss The usual reaction is of shock, guilt, anger, dissapointment or denial. In our social setup, in addition to coping with their own feelings, parents also have to deal with the reaction of the rest of the family members, including the spouse, friends and the society.

Parents need to understand these feelings only then will they be able to deal with their child. The pressures and the strains get intensified at each developmental stage. Very often the mother blames herself or is blamed by others in the family. Misconceptions existing in the society also add to this feeling of guilt.

Parents reaction and behavior with their disabled child varies from **deep concern** (by taking the child from doctor to doctor, or in the rural areas to the faith healers) and **hope** (when friends or neighbours tell them not to worry 'My son learnt to speak very late') to **total rejection**. The conflict of time distribution between the normal and the disabled child is one of the major problems faced by parents.

In such situations parents need professional help. They need to share their problems and seek guidance. In the urban areas counselling and child guidance services are available. Some of these centres offer group counselling programmes which provide an opportunity for parents of disabled children to meet, discuss and share each others concerns. But in the rural areas, where no such help is available, the parents need to talk about their problem to somebody. May be the village Dai, a relative or a friend who is sympathetic or another disabled person who understands the problem and can offer some sensible advice.

It has been accepted that where parents have accepted their child's disability in the early stages, the progress shown by the child has been better than those parents who have taken much longer to accept their child's disability.

At each stage of the child's development there are questions and worries for which they need help. They vary from vocation, sexual needs, marriage, capability of future independence, the possibility of the disability getting worse as the child grows older etc.

Care and understanding are essential for overcoming these feelings of experience of loss. Sharing the problem with other parents who have disabled children helps them to cope with their own feelings.

Families of children with disabilities can get together to form self support groups. Such groups help in giving strength to the parents to cope with their own situations thus reducing their tensions. They share ideas and problems that help clarify doubts and solve problems, eventually helping them in accepting the situation and modifying their attitudes towards their children.

In addition, such parents groups can also play an important role in influencing others in the community and sensitise them to the special needs of people with disabilities.

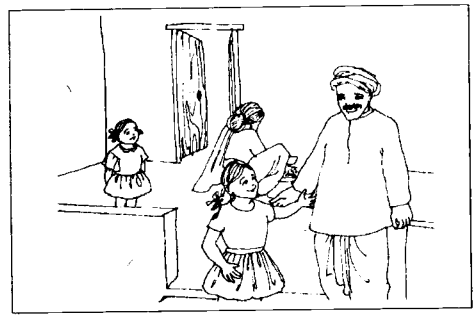
CASE STUDY

This is the story of Seema and Kailash. They had a 6 year old daughter Meena and were looking forward to the birth of another baby in a few months. As is generally the practice in villages and in urban slums, the Dai (traditional birth attendant) delivered a baby girl.



As time passed Seema noticed that the baby Sheela was not doing many of the things that a normal 3 year old should do. She talked to the Dai who told her, "Perhaps the baby's brain is damaged and that is why she did not go through the normal developmental milestones." The Dai suggested that they go to the village rehabilitation center. Here their fears were confirmed Sheela was mentally retarded.

Physically she was growing normally. Her father ignored her, sister Meena was ashamed of having a sister with whom she could not communicate. Accused by the family of having a mentally retarded child, Seema was ashamed, hurt, angry and felt guilty. Her relationship with the entire family suffered.



Finally, a friend suggested to Seema that she and her husband should seek help from a priest or a village elder. Perhaps talking to them about their feelings would help them to cope better with having a disabled child.



So Seema and Kailash went to the temple and talked to the priest who spoke to them gently and counselled them. After many months off regular counselling Seema and Kailash have accepted child's disability and have decided to help her all they can.

Today Sheela a part of the family's activities. Her father loves her and is proud of every new skill she learns. Meena spends a lot of time with her, playing and teaching her simple skills. Seema is not ashamed any more and also takes her out to community functions etc. Seema has also found others who have disabled children. Sharing problems and solutions have helped Seema and Kailash and many other parents like them to cope with the situation.



Genetic Counselling

There are many families where there is more than one child with a disability. If there is already a disabled child in the family and another baby is on the way, the parents need to know the risks involved in having the second child. This is particularly important when the child has Cerebral Palsy (chapter 9) or Down Syndrome (chapter 32) for example or any other birth defect.

In such cases there is need for genetic counselling. Genetic Counselling is given by a team of people consisting of a geneticist, helped by a social worker and a community health worker. They give correct information about the disability as well as inform parents of the options available to deal with the risk of recurrence.

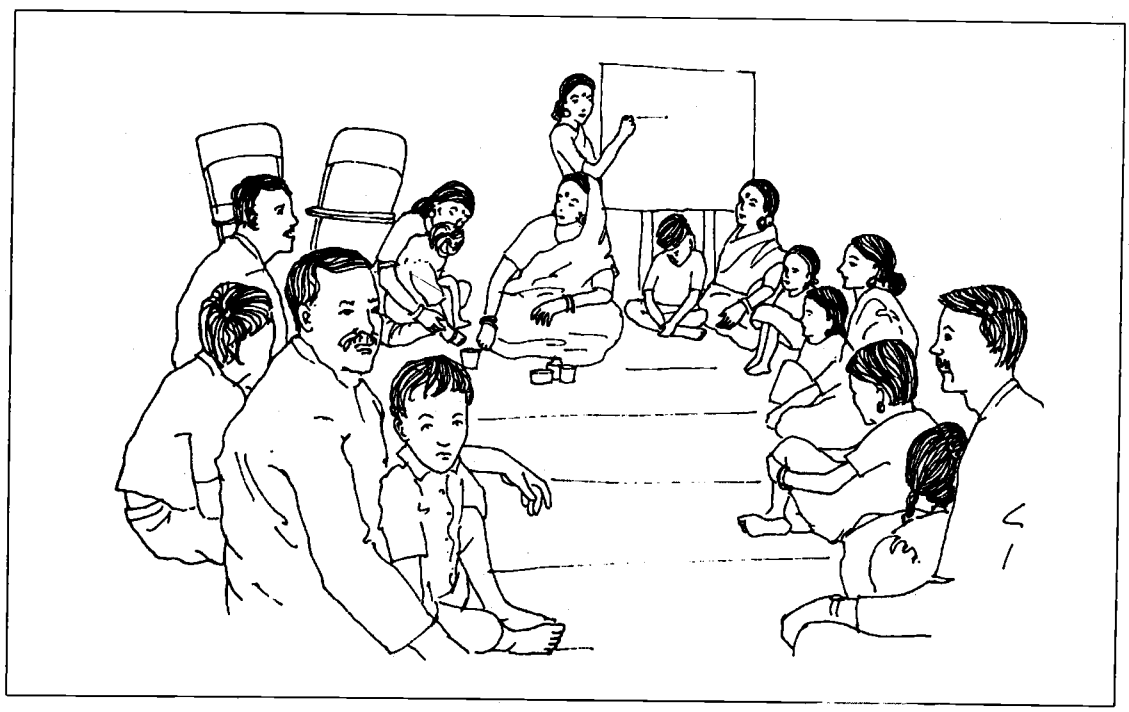
Self-help groups

In our country a large number of disabled people live in the villages. There are no facilities in the form of early intervention, vocational or other programs which we see in urban areas. Here are two examples of self-help groups. One that is made up of parents and families of disabled people and the other which is made up of disabled people themselves.

1. Parents need practical help in understanding the skills which they can apply in actual situations. Parents who care for disabled children often live in great strain, particularly those with severely disabled children. Families thus need a lot of support and help from each other as well as from professionals.

Self help groups evolved by parental interaction plays a very crucial role in making it possible for parents with disabled children to come together for sharing and learning through pooling of their experiences, dissapointments and achievements. It helps families to overcome the stigmas against disabilities by openly discussing their problems and help them cope with their responsibilities- since they function with minimum professional input and maximum parental participation.

Such a group is a multipurpose disability centre which acts as a nodal point in assisting families to develop a range of services and facilities and for parents to find solutions that are relevant to their immediate needs.



The efforts of Seva-in-Action,a Bangalore based voluntary organisation providing services to disabled people, have proved very successful in establishing self support groups in villages around Bangalore and in the Kolar district of Karnataka. Parents and families of disabled children work together to develop a range of services and facilities for their own and other disabled children.

How to promote a self-help group

Remember that a self-help group

- should be evolved by parents.
- should not be formed by professionals or experts.
- should meet the families with disabled children allowing them to discuss their problems. Respect their wish for not wanting to do so in a group.
- should individually help the parents to accept their child with all his abilities and disabilities.
- should share the idea of a self-help group with a few parents. In an emergency encourage them to leave their disabled child with another parent who also has a disabled child. This helps to develop mutual support and strengthens the rapport between parents.
- should encourage them to meet a few hours a week and allow them to discuss their problems and issues and play the role of the 'mediator'. Help them find simple solutions. It is important for them to feel that "this may work".
- Finally when the parents organise themselves into a self-help group to function every day for a few hours, plan activities for each child in different areas of development.
  To organise a successful self-help group it is important to train parents in the skills that are required and relevant to their immediate needs. For example if there is a mentally handicapped child who is not toilet trained and if the parent feels that this is of utmost priority then train the parent in the skills required for toilet training the child.
  Local village headman, priest or teacher, if involved and encouraged to take an active interest can help in making a success of the group. The participation of the community members helps in changing the attitudes of the people toward the disabled children.

2. Disabled people are motivated to form their own SANGHAM or organisations through a process of animation. This slow and long process gives disabled people the space and time to reflect on their situation, build self-confidence in their ability and find strength in being together as a group. This process also enables them to identify their needs and the best ways to fulfill those needs. For example many of the disabled persons did not have medical or income certificates which are the primary need for availing any government assistance. So they decided to first get them and on the basis of this many applied for income generating schemes which were sanctioned.

The aim of **ADD** (Action on Disability and Development) organisations is to promote self-help among disabled people in poor communities. **ADD** works in several countries. Their strategy in India is to facilitate existing voluntary organisations to work with disabled people to promote self-help so that ultimately leadership qualities can be developed and disabled people can make their own decisions and manage their programs.

Development work with disabled people is a part of the voluntary organisation which has a partnership with ADD India. Partnership with four agencies working in Andhra Pradesh and Tamil Nadu have resulted in the establishment of 94 self-help groups or sanghas with a total membership of about 1121. Field workers involved in the task cover several villages and support disabled people in forming groups and help them in whatever they want to do.

These sanghas play an important role in helping disabled people to improve their social and economic status in the community so that they can effectively manage their own lives and be an active member of the village community.

Dr. Bindu Prasad - Clinical psychologist and special educator.
Understanding M.R. and Genetic Counselling Tata Institute of Social Sciences.Bombay.
To know more about how to form self-help groups write to :~
Sewa-in-Action,
Action on Disability and Development,
10 Norris Road,Richmond Town, Bangalore.



NOTES

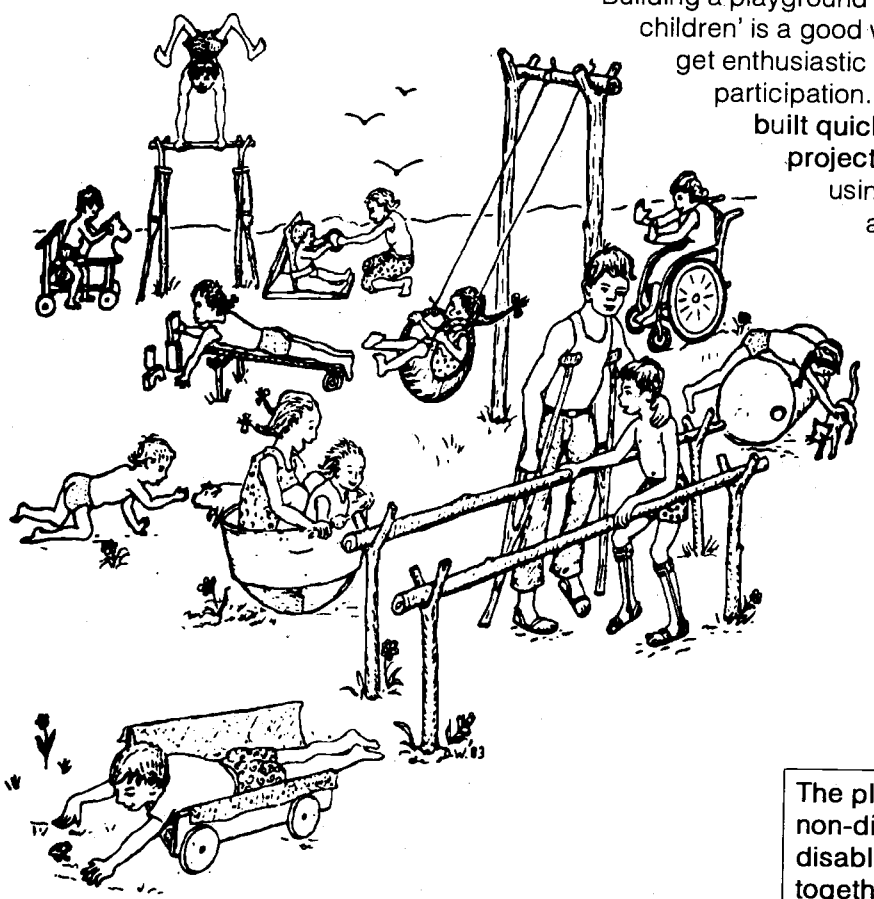
CHAPTER **47**

Playgrounds for All Children

A good way to start a village or neighborhood **rehabilitation** program is to involve the local people in building a low-cost 'rehabilitation playground'. It is important that the playground be built **for use by all children - both disabled and non-disabled.**

With a little help from adults, the local children can build most of the playground themselves. To prevent the playground from being destroyed or vandalized, you may wish to invite some of the roughest local children and 'gang leaders' to help lead the project. Or you can appoint them as 'maintenance chiefs'.

Building a playground 'for all children' is a good way to get enthusiastic community participation. It can be **built quickly** as a **group project** at **low cost** using **local resources** and gives quick, easily seen, fun results.



The playground brings non-disabled and disabled children together through play.

To build a playground, it is best to **use local, low-cost materials,** and **simple construction**. One of the playground's main purposes is to give disabled children and their parents a chance to try different playthings and exercise equipment. Whatever works for their child, a family can easily build at home, at no or low cost. For this reason, a playground made of tree limbs and poles, old tires, and other 'waste' materials is more appropriate than a fancy metal playground built by skilled craftsmen at high cost. (Also, metal gets very hot in hot, sunny climates.)

These pages will give you some ideas for simple playground equipment. Although most of the photos come from PROJIMO in Mexico, many of the ideas shown are based on a playground in Thailand (see p. 519) and on designs by Don Caston (see p. 774).

A 'playground for all' built by children - PROJIMO, Mexico

When disabled village health workers in the small village of Ajoya decided to start a rehabilitation program for disabled children, one of the first activities was to involve the local children in building a playground.



1. First the children went into the forest to cut poles and vines.



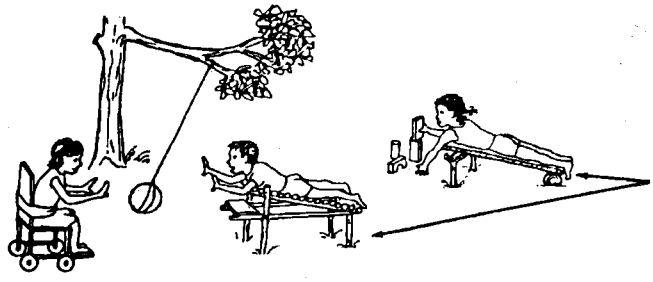
2. These they brought back to an empty lot at the edge of the village.



3. While some children cleaned up the lot, others began to build the playground equipment.

4. They built ramps or 'wedges' like this one, which can be used in many ways for play and exercise. Here a child with cerebral palsy walks up the ramp to help improve balance and stretch his feet upwards to prevent contractures.

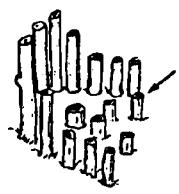




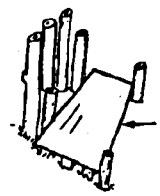
The wedges can also be used for severely disabled children to lie on, so that they can lift their heads and play with their hands.



Pole seats like this help a child sit who still lacks balance, or has trouble controlling his position.



These separators will hold apart the legs of child whose legs pull together (spasticity).



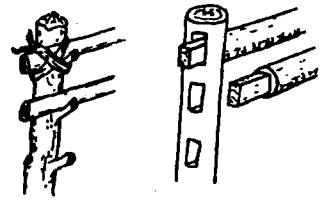
Putting front posts the same height allows a shelf to be placed for play.



Simple parallel bars can be used as gymnastic bars by the able-bodied children.

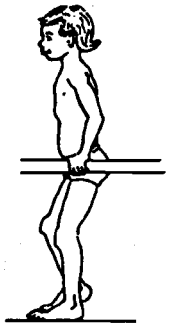


and as bars for learning to walk by disabled children.

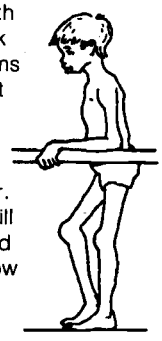


Bars need to adjust to different heights for different children. Here are 2 simple ways.

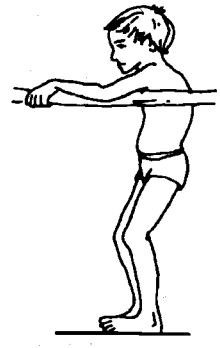
For most children, the bar should be about hip height, so that the elbows are a little bent (the same height as the handles of the crutches).



A child with very weak upper arms may find it easier to rest his forearms on the bar. The bar will be needed to be elbow high.

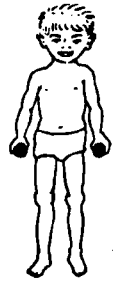


A child who tends to slump forward may be helped to stand straight if the bar is high, so that he has to stand straight to rest his arms on it.

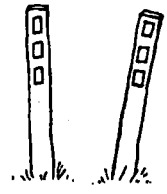


SEPARATION OF BARS

Bars should be close enough to leave only a little room on either side of the child's body. Too close, they get in the way. Too far apart makes weight bearing more difficult.

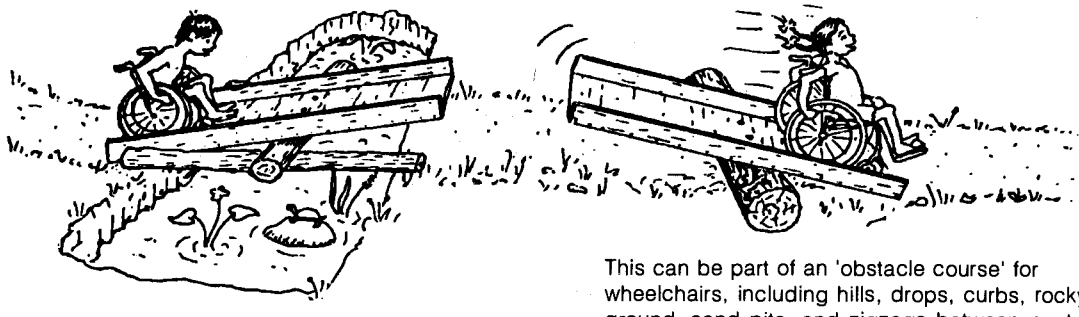


Smaller children require closer bars. Therefore, put uprights so they are wider higher up.



Simple, homemade bars, adjusted to the individual child's needs, often provide more benefit than expensive walkers or other equipment.

TEETER BRIDGE

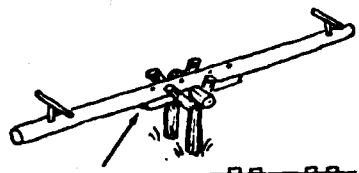


This can be part of an 'obstacle course' for wheelchairs, including hills, drops, curbs, rocky ground, sand pits, and zigzags between posts.

A simple seesaw or **teeter-totter** like this is fun and helps disabled children gain balance. The one in the photo was made by putting a pole in the crotch of a mango tree.

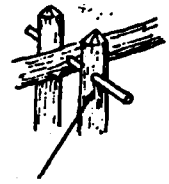


Rocker supports for a seesaw can be made in many ways.



Some sort of blocking is needed to keep pole from sliding or rolling.





One way to prevent rolling and rotating is to pass a metal pipe through the pole.



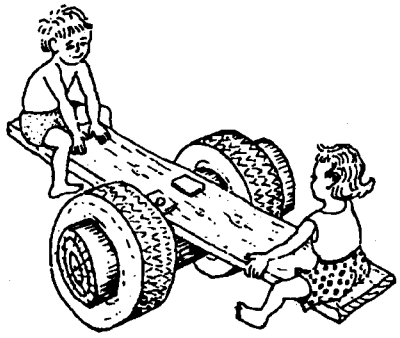
One end of this seesaw has an enclosed seat for a disabled child. Space is left behind for an able-bodied child to sit and protect the disabled child.

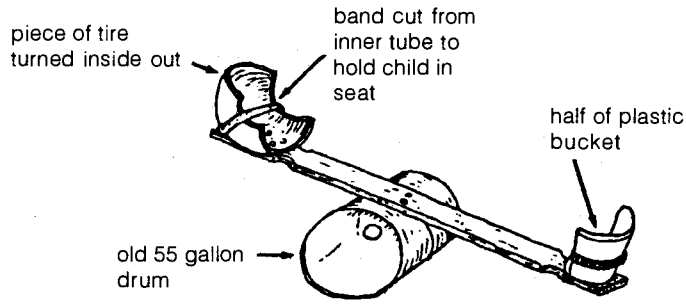




On the other end a wooden donkey head adds fun.

Here are some other ideas for seesaws.





PRECAUTIONS

1. To avoid accidents, be sure the pole for the seesaw is strong enough. Test it every few weeks by having 2 adults put their full weight on the ends of the pole.
2. To avoid coming down too hard, put old tires under the ends of the seesaw (see p. 519).
3. Make sure the seesaw will not roll lengthwise or sideways (see above).

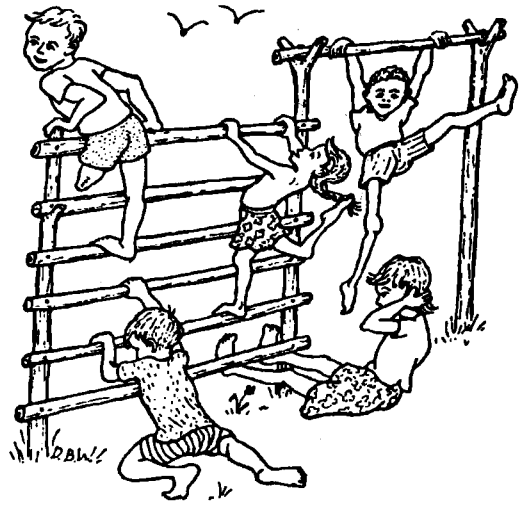
For another seesaw idea, see p. 519.

CLIMBING FRAME AND HIGH BAR

Children can make a simple climbing frame out of poles, by nailing them or tying them together with string.

The climbing frame can be used for all kinds of play, for helping disabled children pull up to a sitting or standing, and for therapy exercise.

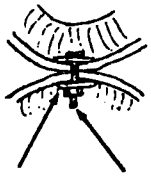
High bars (horizontal bars) at different levels for different children can be used for exercise and gymnastics.



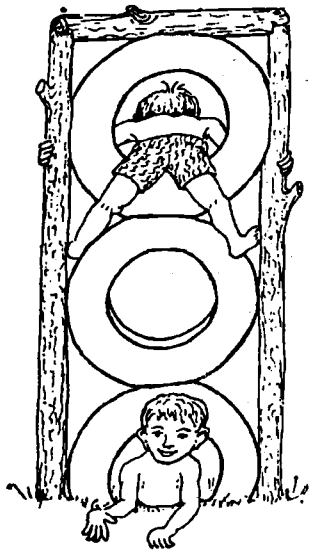
TYRE GYM

Climbing gyms can be made out of many materials, including old tyres.

Gym will be more solid if tyres are bolted together.



washer or metal plate — bolt



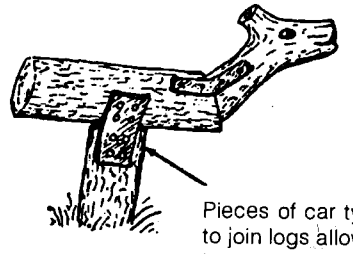


The children in the village of Ajoya, Mexico helped those in the nearby town build their own rehabilitation playground. This tire climbing gym was one of the playthings they created.





Building and riding a rocking horse made of logs.



Pieces of car tyre to join logs allow horse to rock back and forth.

SWINGS

A wide variety of swings can be built out of different local materials. Swinging is fun; it can help develop balance, head control, coordination and strength. Swings with special features can be built for the needs of particular children.



Here children in PROJIMO make an enclosed swing.

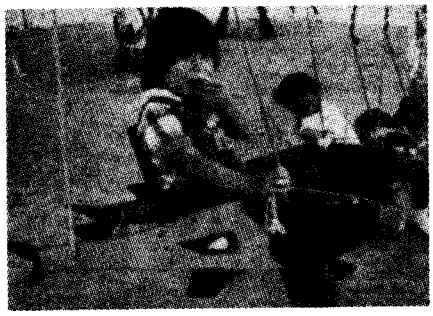


This child with cerebral palsy had never had a chance to swing before. At first he was afraid...



but after a while, he loved it.



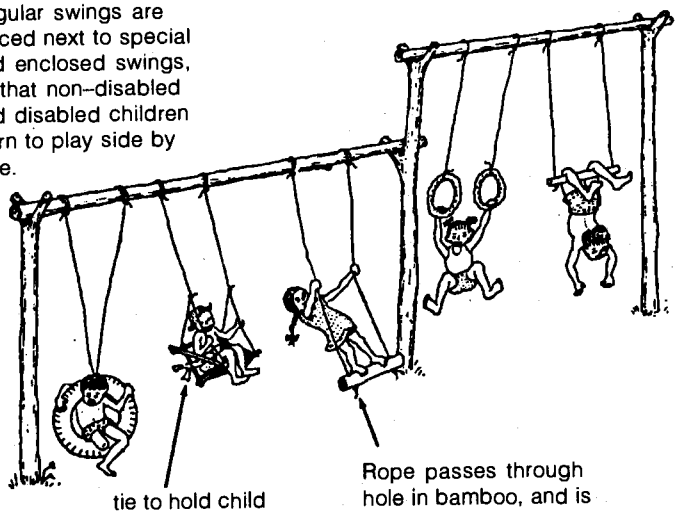


Swings in the form of animals or fish add to the fun.



Extra wide swings allow 2 children to swing together – one assisting the other.

Regular swings are placed next to special and enclosed swings, so that non-disabled and disabled children learn to play side by side.



tie to hold child in swing

Rope passes through hole in bamboo, and is knotted.

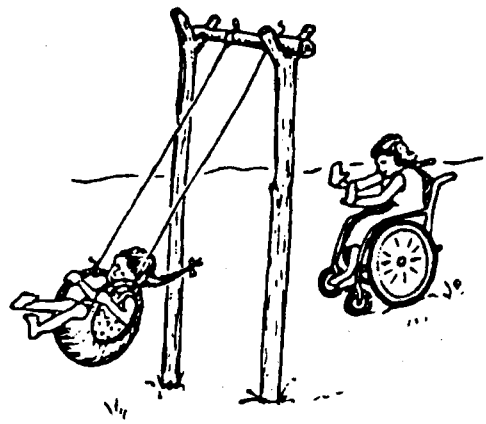


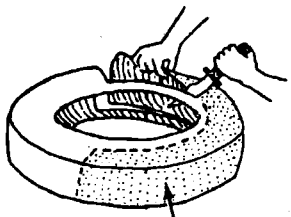
Rings for swinging and many games can be made by cutting out the inner rims of old car tyres.

SWINGS AND PLAYTHINGS USING OLD TYRES AND TUBES

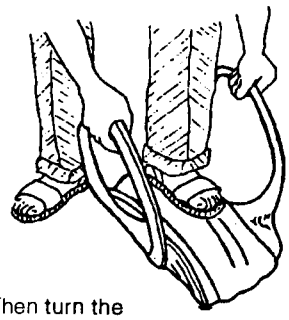
This swing made of old tire is especially good for children with spasticity because it bends their backs, heads, and shoulders forward.



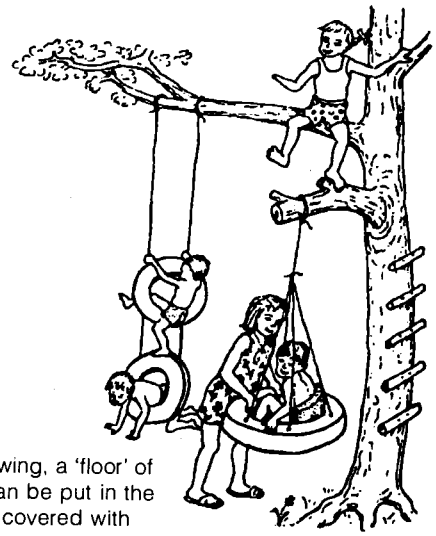




Cut away this part of the tire.



Then turn the tire inside out.

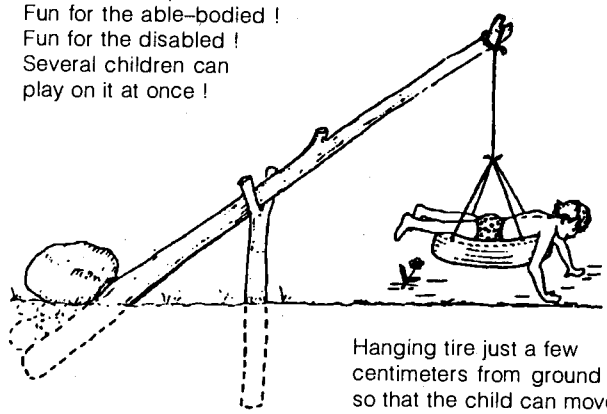


In this swing, a 'floor' of sticks can be put in the tire and covered with straw or a mat.

This flat-hanging tire is especially useful for the severely disabled or delayed child who is just beginning to learn to move his body. The child can lie across the tire and move this way and that by pushing the ground with his hands.

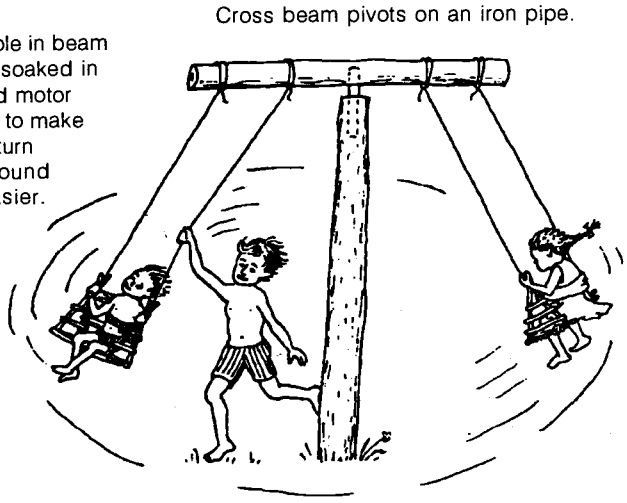


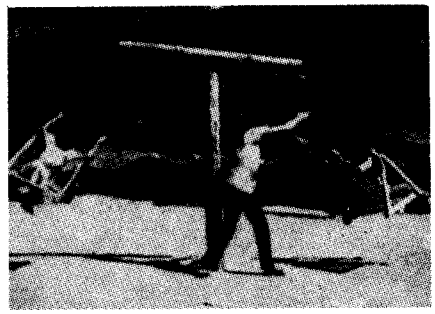
It swings ! It spins ! It bounces !
Fun for the able-bodied !
Fun for the disabled !
Several children can play on it at once !



Hanging tire just a few centimeters from ground so that the child can move with his hands.

WHIRLYGIG CIRCULAR SWING





Circular swing in PROJIMO rehabilitation playground. (Here the child pushing the swing has cerebral palsy. The twisting motion he uses is excellent therapy.)

CAUTION : Be sure both the pole and beam are of strong hard wood. Test them occasionally with adults' weight.

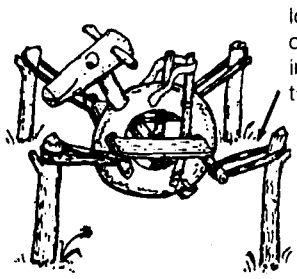
BOUNCING TUBE (from *Low Cost Physiotherapy and Low Cost Walking Aids*, see p. 774.)



Piece of strong canvas stretched tight over large truck or airplane inner tube.



BOUNCING TIRE HOBBY HORSE



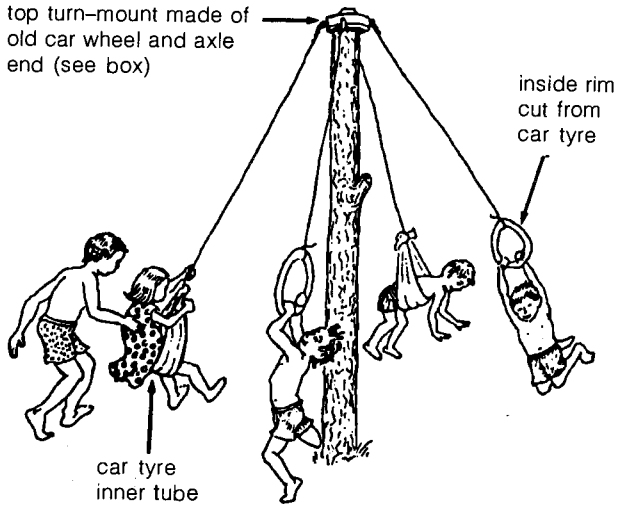
Be sure to notch poles and attach tubes so they do not slip.



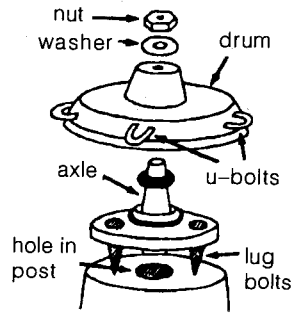
Note : It is much easier to put holes through tyres that do not have steel wire in them.

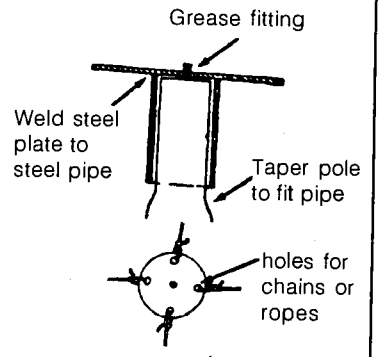
MAYPOLE

Disabled children who can sit and hang on can play with non–disabled children on the maypole. But to start turning round the circle, they may need another child to help push them.



HERE ARE 2 WAYS TO MAKE A TOP TURN MOUNT

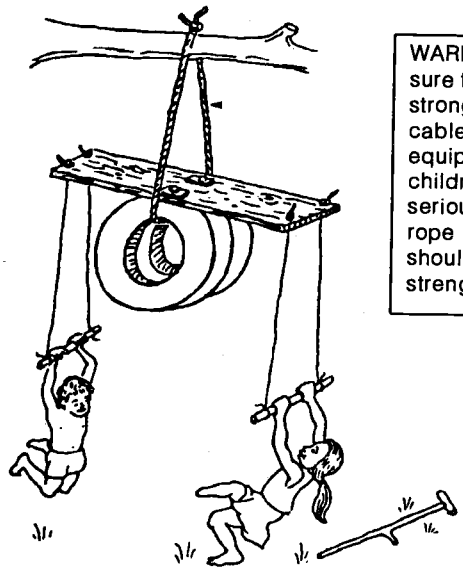




STEEL PLATE – TOP VIEW

fasten chains with "S" hooks.

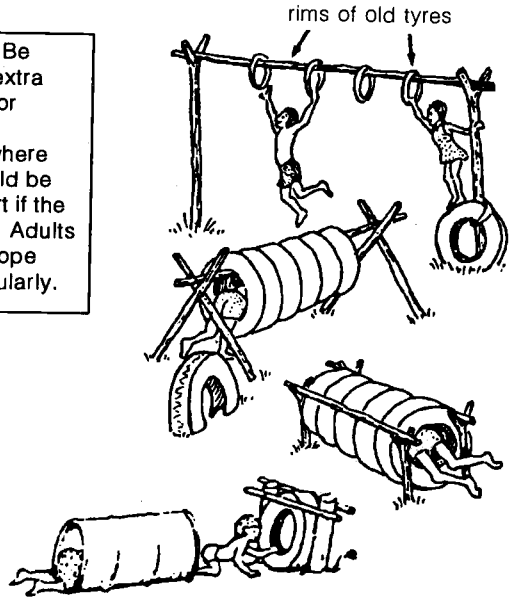
HANGING SEESAW SWING



WARNING : Be sure to use extra strong rope or cable in any equipment where children could be seriously hurt if the rope breaks. Adults should test rope strength regularly.

The weight of the tyres adds stability for smoother swinging.

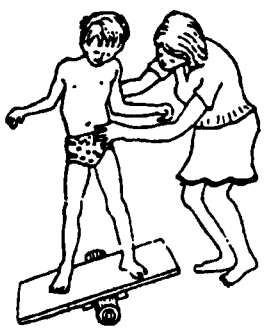
OBSTACLE COURSE



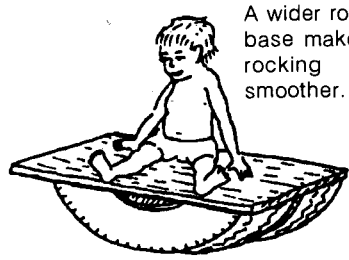


Old tires and drums can be used for crawling games and obstacle courses.

BALANCE BOARDS







A wider rocker base makes rocking smoother.

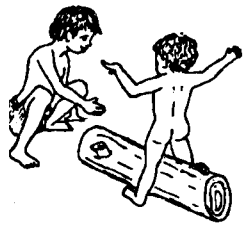
For the rocker you can use 2 pieces of old tyre.

For more balance boards and balance beams, see p. 700.

ROLLS





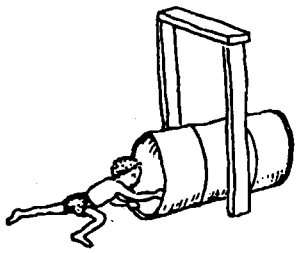




A row of half buried out old tires. The tires sink in when stepped on. A test of balance and great fun !

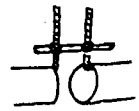
Old barrels, oil drums, paint cans, and logs make good playground equipment–for therapy and fun.

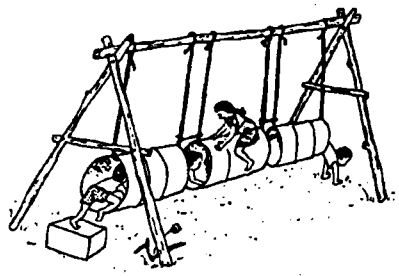
CRAWL–THROUGH DRUMS



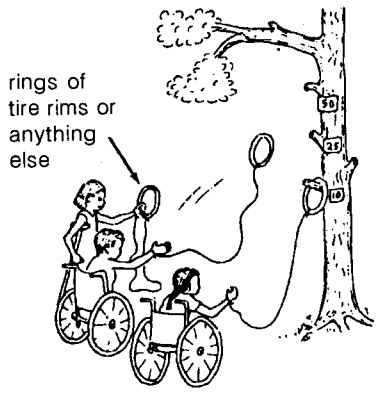
HANGING CRAWL–THROUGH DRUMS

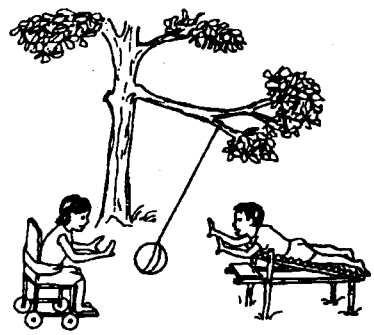
CAUTION : Hold drums apart with sticks to prevent smashed hands and feet.





RING–TOSS

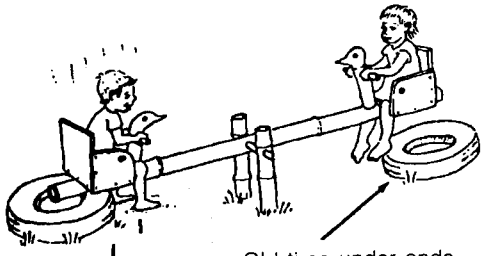




For children who have trouble going after dropped balls or rings, tying a string to the toy allows the children to pull it to them.

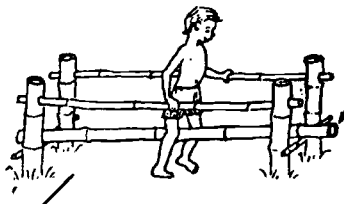
Examples from the 'bamboo playground' in the Khao–i–dang refugee camp, Thailand

SEESAW with enclosed seats



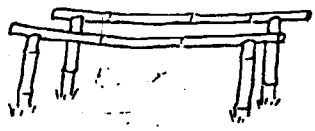
Old tires under ends of seesaw act as 'shock–absorbers'.

PARALLEL BARS for a child whose knees pull together



Smooth bamboo pole between legs helps child learn to walk with knees separated.

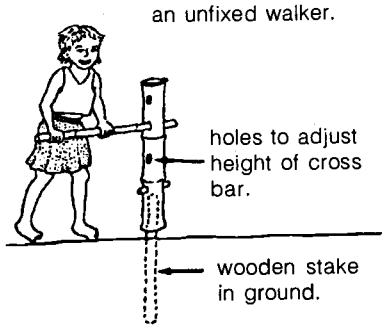
HIGHER PARALLEL BARS for taller child



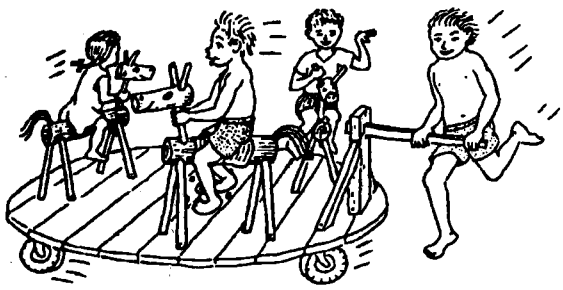


CIRCULAR WALKER

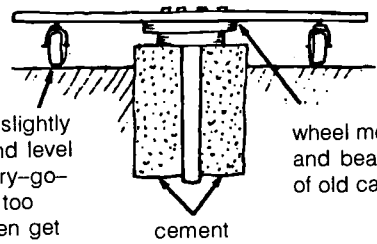
Especially good for the child whose sudden uncontrolled movements may knock over an unfixed walker.



MERRY–GO–ROUND



One way to mount the platform of a merry–go–round.



Small wheel slightly above ground level protect merry–go–round when too many children get onto one side.

PRECAUTIONS AND SUGGESTIONS FOR A SUCCESSFUL ALL–CHILDREN'S PLAYGROUND

1. Involve as much of the community as possible in building and maintaining the playground.

2. Keep the playground simple and build it from local low–cost materials. Only this way can it serve as a model for families of disabled children to build the most useful equipment for their child in their own homes. resist offers from the local mayor or politicians to build an impressive metal frame playground, This will eliminate community participation and makes the equipment too costly for poor families to build at home.

3. For poles that are put into the ground, use a kind of wood that does not rot quickly. Or paint the posts with old motor oil, creosote, tar, copper sulfate or some other insect and fungus resistant substance.

4. Swings can be hung from ropes or chains. Rope or vines are cheaper but may rot or wear through fairly quickly. Plastic or nylon rope will not rot in the rains, but will gradually grow brittle and weak with the sun. As with posts, **to avoid accidents, check strength of ropes frequently** by having several heavy persons hang on them at one time. **Replace ropes at regular intervals,** before they get weak.

5. Regular maintenance of the playground is essential, and this will require planning and organisation. Perhaps once a month the village children can take an expedition to cut new poles to replace rotting ones, to repair old equipment, and to build new. Adult coordination of such activity is usually necessary.

6. To boost enthusiasm, keep lists in a public place of all the children and adults who help with the playground – and put a star for each time they help.



Children play on a 'merry–go–round' in PROJIMO. Enclosed 'cars' protect more severely disabled children.

CHAPTER **48**

CHILD-to-child

Helping Teachers and Children Understand Disabled Children



Children can be either very cruel or very kind to a child who is different. They may be cruel by teasing, laughing, imitating, or even doing ***physical*** harm. But more often they are cruel simply by not including the disabled child in their games or activities, by rejecting the child, or by pretending she does not exist. Often children act in a cruel way because they fear what they do not understand. **When they gain a little more understanding, children who may have been cruel or felt uncomfortable with the child who is different, can become that child's best friends and helpers.**

It is important that children in every neighborhood or community have a chance to better understand persons who, for whatever reason, are different from themselves–in color, in dress, in beliefs, in language, in movements, or in abilities.

One way to help a group of children gain appreciation of the disabled child and learn ways to be helpful is through **CHILD-to-child activities.**

CHILD-to-child is a non-formal educational program in which school-aged children learn ways to protect the health and well–being of other children - especially younger children and those with special needs. The children learn simple preventive and curative measures appropriate to their own communities. They pass on what they learn to other children and their families.

The CHILD-to-child program began during the International Year of the Child, 1979. David Morley (author of **Paediatric Priorities in the Developing World** and **See How They Grow)** brought together a group health workers and educators from many countries. They designed a series of 'activity sheets'- or guidelines - to be adapted by teachers and health workers for children in different countries and situations.

Six activity sheets about disabled children have been put together in a packet, together with a booklet called ***"Do You Know a Handicapped Child?"*** The set is available through Teaching Aids at Low Cost (TALC), P.O.Box 49, St. Albans, Herts. AL1 4AX, United Kingdom. The activity sheets in the packet include:

- *Handicapped children*
- *Polio: How children can help*
- *Let's find out how well children see and hear*
- *Looking after the eyes*
- *Helping the severely deaf child*
- *Understanding children's feelings*



Other activity sheets available from TALC that include ***disability*** prevention are:

- ***How do we know if our children get enough food?***
- ***Healthier foods for babies and children***
- ***Care of children with diarrhea***
- ***Accidents***
- ***Our neighborhood - making it better***
- ***Playing with younger children***
- ***Toys and games for young children***
- ***A place to play***
- ***Caring for children who are sick***
- ***Better health habits***

CHILD-to-child activities can be introduced:

- by schoolteachers with schoolchildren,
- by schoolchildren (who have practiced the activities in school) with younger school-children, or with children who do not go to school,
- by health workers or community ***rehabilitation*** workers,
- by parent groups or any concerned persons in the community.

The purpose of CHILD-to-child activities that relate to disability is to help children:

- gain awareness of different disabilities and what it might be like to be disabled,
- learn that although a disabled person may have difficulty doing some things, she may be able to do other things extra well,
- think of ways that they can help disabled children feel welcome, take part in their play, schooling, and other activities, and manage to do things better,
- become the friends and defenders of any child who is different or has special needs.

From the CHILD-to-child activity sheet:

ACCIDENTS

Help children learn how important it is to:

- Make sure that their younger brothers and sisters do not go too close to the cooking fire.

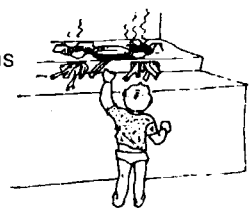






- Keep matches out of the reach of small children. (They can even make a small basket or shelf for matches to be stores high on the wall.)

- Be sure that handles of pans are turned so that the child does not pull them.

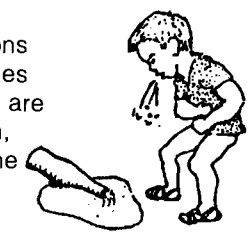




- Warn younger children about where snakes, scorpions, and bees live.

- Clean grass and weeds away from paths.

- Make sure poisons such as medicines and insecticides are kept out of reach, and that kerosene is not stores in drink bottles.



Rehabilitation programs in several countries have developed their own, more complete CHILD-to-child activity sheets. Here we combine versions from Kenya (Africa), the Philippines, and Mexico (where some of the original sheets were developed and tested). The 3 activities we include in this chapter are:

"Understanding children with special problems" (p. 523)

"Children who have difficulty understanding" (p. 536)

"Let's find out how well children see and hear" (p. 541)

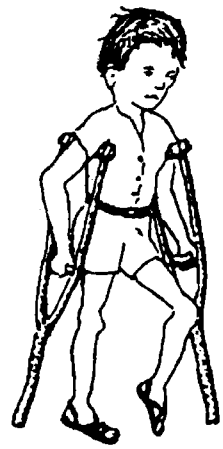
CHILD-to-child ACTIVITY:

UNDERSTANDING CHILDREN WITH SPECIAL PROBLEMS

Group discussion

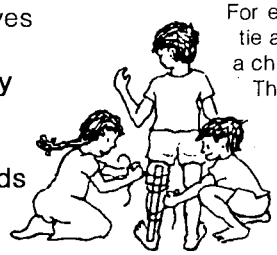
Encourage a class or group of children to talk about children who have some special problem or 'handicap'. Ask questions like:

- Do you know any child who cannot walk or run or talk or play like other children?
- Why can't this child do everything the same as you can?
- Is the child to blame?
- How do other children treat this child? Are they kind to him? Are they mean? Do they make fun of him? Do they include him in games?
- How would you feel if you had a similar problem? How would you want other children to treat you? Would you like them to laugh at you? To pay no attention to you? To feel sorry for you? To do things with you and become your friend?



Games and role playing

Children will better understand the child with a special problem if they can 'put themselves in his shoes'. They can **play a game in which one child pretends to have a handicap.**



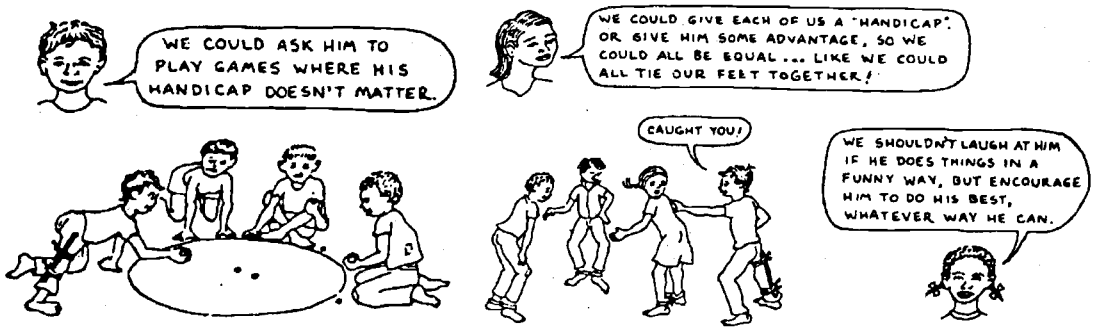
For example, tie a stick to a child's leg. Then have him run in a game or play tag.

The other children act out different ways of behaving toward the child. Some are friendly. Some ignore him. Some make fun of him. Some help him. Some include him in their games. Let the children think up their own ideas and act them out.

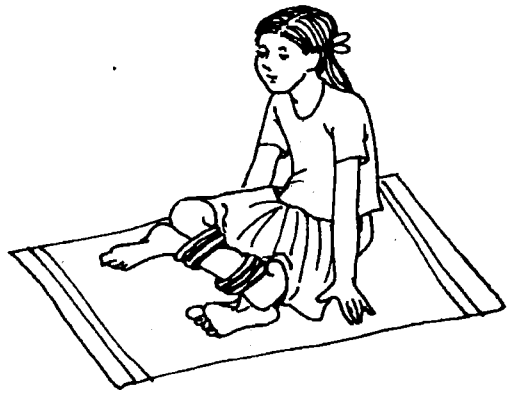


After several minutes, another child can pretend to have a handicap. Let several children have a turn with a handicap. Try to make the pretend handicap seem real.

Also ask the children what they might be able to do to make things better or fairer for the disabled child. Try or 'act out' their different suggestions. For example:



For a more severe physical disability, the group of children can invent ways to 'find out what it is like'. For example, to learn about a child with almost no use of her legs, the children might tie the legs of one of their group together, like this.



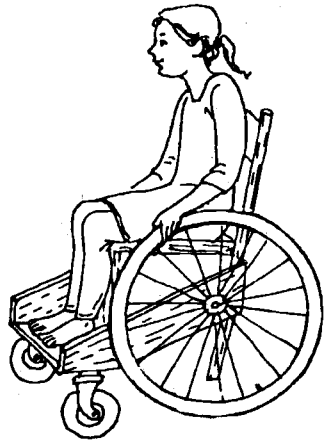


Then the children can ask the child to do some of their day-to-day activities-like moving around the house, going to the latrine, and going to school.

After talking with the child about her difficulties, the children can try to think of ways to make it easier for her to move about.







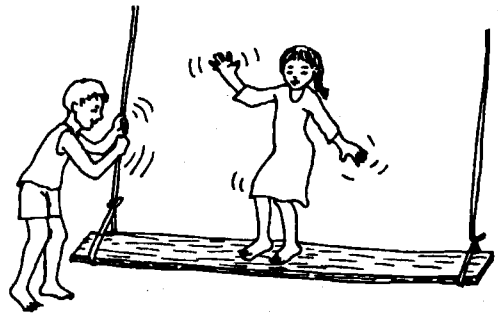
Note: With the help of their teacher or parents, children can, in fact, make simple wheelchairs and other aids for disabled children. For simple designs, see PART 3 of this book.

REMEMBER: Children are usually kind to a child with a very severe disability. They are often more cruel to a child with a less severe problem, such as a limp.

Help the children gain an understanding of the particular difficulties of any disabled child in their village.

For example, if there is a child with spastic legs who has trouble walking because his knees press together, have a child try to walk with her knees tied together with a band of car tire inner tube.





To appreciate the problems of a child who has trouble with balance (cerebral palsy), have one of the children try to walk on a hanging board (or other moving surface).

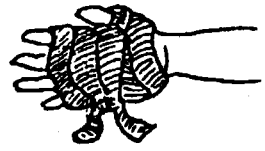




If there is a child with arthritis in the village, some of the children can put small stones in their shoes or tie feet. Then the other children can invite them to run and play games. Ask the children why a child with arthritis might not want to play games.

Ask the children, "Do you know any children who cannot use their hands like you can?" If they answer yes, help them experience the difficulties of such a child. Have the children work in pairs.

One child can wrap a strip of cloth around the other child's hand and fingers so that he has trouble moving his fingers.

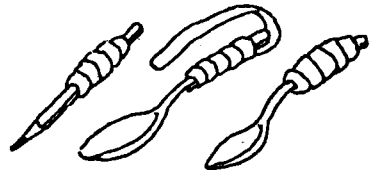


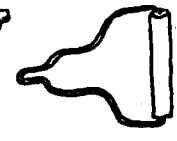
Now have the child try to do things like:

- write
- turn pages of a book
- fill a cup with water
- eat
- get something from a pocket
- button a shirt



Have the children try to figure out ways to make it easier. For example, wrap cloth or a piece of inner tube around a pencil or spoon, to make it easier to hold.



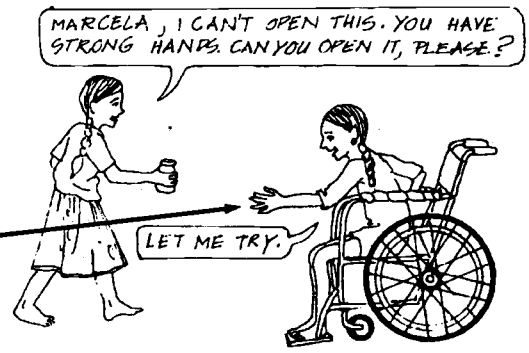


buttoning tool (see p. 410)

Note: For more ideas and tools for persons with disabled hands, see pages 264 and 402.

Things that a disabled child can do well

A disabled child cannot do **everything** as well as other children. But often there are **some things** she can do as well, or even better. Try to have the children think of examples.



A child with weak legs, who has to walk with crutches, often develops very strong arms and hands.

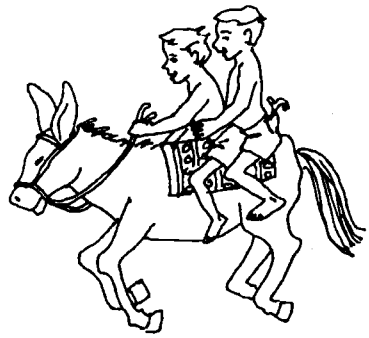
Or a blind child may learn to hear things extra well.

Rather than feel sorry for the disabled child and look only at her weaknesses, **it is better to recognize and encourage her** strengths.

A LETTER TO ALL CHILDREN:

A handicapped child needs friends, play, and excitement–just like you. Try to include the child in your games and adventures. Let him do as much for himself as he can, and help him only when he needs it. But remembers, he cannot do everything you can. Protect him from danger...but do not protect him too much! Too much protection is dangerous to any child's health. Children need adventure for their minds to grow, just as they need food for their bodies to grow.

Thanks



Swimming



Many children with weak or ***paralyzed*** legs can learn to swim well. Their arms become unusually strong from using crutches, and in the water they easily keep up with other children. But sometimes they have trouble getting to the water, or the other children forget to invite them....





A friendly word of welcome to include the child with a special problem, or a little extra time or attention given to him, can make a big difference – and can make everyone feel good.





Role playing and children's theater

To help see how much it matters to include a disabled child in their fun, a group of children can act out different possibilities. For example, they might act out (or do a 'role play' of) the pictures at the bottom of the page before this one. After the role play the group can discuss which of the two alternatives made the disabled child, and the other children, feel better, and why.



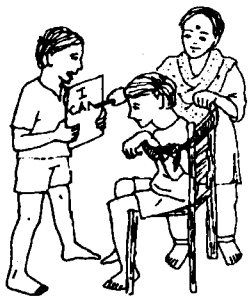


Photos from Ajoya Mexico

Or they can act out a situation in which they try to solve a particular difficulty, obstacle, or challenge.

For example, there is a bright little girl who has no control of her arms or hands, but fairly good movement of her head and one foot. Can the children figure out a way to help her write? The class divides into 3 or 4 groups to try to solve the problem.

One group might think of helping her to write with her head.



Another, with her mouth



And another, write with her foot.



In these ways the children will begin to use their imaginations to help solve problems.

If some of the children's role plays turn out especially well, or do an extra good job at demonstrating important points, perhaps they can be developed further. Then the children can present them, in the form of skits or children's theater, to other classes, parent groups, in the health center, or perhaps to the whole village.

(Examples of two skits which schoolchildren, together with health workers and disabled rehabilitation workers, put on in the village of Ajoya, Mexico, are on pages 553 to 556.)

Putting our new understanding into practice

Once the children have developed a greater awareness of the needs and possibilities of disabled children through discussion, games, role plays, and stories, they can begin to put their new understanding into practice.

Ask the children if they know any child in the village (or in a neighboring village) who is disabled or has special difficulties in any way.

Then discuss ways that the children might be able to help each disabled child become as happy, capable, and self-reliant as possible. The children can list their suggestions for each child. Later, after getting to know the child and her family better, they can change and add to their ideas.

It the disabled child is a brother or sister of one of the children in the learning group, starting to do things with the child and the family may be fairly easy. But if none of the children are related to the disabled child, they must be careful in the way they offer their help. Probably only two or three children should make the first visit, perhaps with the help of a teacher, health worker. or rehabilitation worker.

The children, with suggestions from the disabled child and her family, will need to figure out ways that they can help most. However, the following list of possibilities may give you some ideas:

- Become friends – one or more children can become close companions, playmates., and friends of the disabled child.
- Visit the child at home – regularly!
- Help the family by doing errands, 'baby-sitting' or taking the child on outings.
- Figure out a way to help the child get to and from school.
- At school, one or more children can become the 'buddies' or helpers of the disabled child making sure her special needs are met.
- If it is impossible for the disabled child to go to school, children may be able to organize an after-school teaching program at the child's home. Ask the teacher to help plan this.
- Figure out ways to include the child in games.
- Make helpful toys for the child and play together with her. (See p. 562 to 573.)
- Make a 'rehabilitation playground' or 'playground for all children'. Take disabled children regularly to the playground and play together with them there.



REMEMBER–
ALWAYS BE FRIENDLY

- Build simple playground equipment, adapted for the particular child, at her home.
- With advice from a rehabilitation worker or the child's parents, learn to help with the exercises or care that the child needs.
- You may be able to help build special aids for the children, such as crutches, sandbags, braces, or even a simple wheelchair. Try to get advice from a rehabilitation worker. If what you need to make is too difficult, perhaps the children can ask parents who are crafts persons to help. Visit them as a committee.
- Become 'prevention scouts' by following the suggestions–on p. 522, or by taking other actions to prevent disability in your village.
- If there is a village rehabilitation center in your village, perhaps a group of children can take turns there as volunteers after school. There are many ways you can help and much you can learn. Those who show most interest can become 'junior rehabilitation workers'.



A rope swing like this can help a child with weak legs teach herself to walk-in a way that is fun!

Children with severe disabilities

Some children are very disabled. They cannot walk or swim or play many games. But sometimes these children can learn to play marbles, cards, or guessing games.

Learning is especially difficult for a child who cannot speak or think as easily as other children. This child may be very lonely. Sometimes a child who cannot speak, understands a lot more than people think he does. If there is such a child in your neighborhood, perhaps children could take turns visiting him, to talk or play with him. Let him know you care.

Babies with Problems

Sometimes a baby is slower than most to develop. Either her mind may be slow to develop, or her body, or sometimes both. The child will be later than other babies in the village to begin to sit, use her hands, crawl, walk or talk.

Babies who are slow to develop need special care. If possible, their parents should get advice from a rehabilitation worker or ***physiotherapist.*** However, **there is a lot that brothers and sisters and other children can do.**

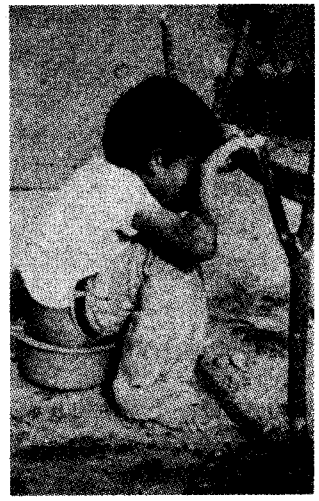
More than almost anything else, **these babies need lots of attention.** They need to be **played with** and helped or encouraged to play. They need **simple toys** and **colorful or noisy things** to attract their attention. They need to be **talked to** and **sung to a lot.** These things will help the baby develop faster. And these are all things other children can do.

In the next activity sheet (p. 536) we will talk more about helping a child whose mind develops slowly or who has difficulty understanding.

Helping a disabled child learn to do new things

There are many ways that children can help a baby or young child with a special problem to learn to do new things. Here are some ideas:

- **Make it fun!** If exercises can be turned into games, the child will learn faster and everyone will enjoy it more.
- **Self-help.** Help the disabled child only as much as he needs. Encourage him to do as much as he can for himself and by himself.
- **Little by little.** Remember, some things are especially difficult for the disabled child. Encourage her to do a little more than she already does–and then a little more. If you have her try to do too much, she may get discouraged and stop trying.
- **Show you care.** Show the child how glad you are when he learns to do new things. Praise him when he does well–and when he tries.
- **Mind and body.** Play often with the child, in ways that help her develop not only her body but also her mind. Talk with her and tell her stories. Become her friend.



A simple bar held by forked sticks can increase the self-reliance of a child who has difficulty squatting to shit.

AN EXAMPLE: Karan is having trouble learning to crawl. Using the above suggestions, how can we help him ? Perhaps his older brothers and sisters, or other children, can play 'crawling games' with him.



Two children can hold up part of his weight as he tries to crawl. Another child encourages him to crawl by holding out a fruit or toy. Call him to crawl toward the fruit. Praise him when he tries.

Play the game every day. As Karan grows stronger, less of his weight will need to be held up. In time he may be able to crawl without help.



Children in Mexico playing a 'crawling game'.

> *Note:* Many more ideas of ways children can help a child who is slow to develop can be found in PART 1 of this book, especially Chapters 35 and 36.

Story telling

Story telling is another good way to help young people understand the needs and possibilities of disabled children and what can be done to help. You can make up stories. Or better, you can base them on true events where a disabled child has achieved something outstanding, or where a group of children have succeeded in making an important difference in the life of a disabled child. The story that follows is an example.

A Story-to be used with the CHILD-to-child activity,

"Understanding Children with Special Problems"

HOW PAWAN AND OTHER CHILDREN HELPED MUNNI GO TO SCHOOL

At age 7 Munni's world was so small that you could throw a stone clear across it. She had seen almost nothing of her own village. No one ever took her anywhere. The farthest she had ever crawled was to the bushes just outside the small hut where she lived with her family.

Munni was the oldest of 3 children. Her family's hut was at the far edge of Bella Village. The hut was separated from the main footpath by a long, steep, rocky trail. Perhaps for this reason, Munni had missed being *vaccinated* in her first year of life, when health workers had come to the village.

In the beginning, Munni had been a healthy baby, and quick. At 10 months of age she was already able to stand alone for a few seconds, and to say a few words, like 'mama', 'papa', and 'wawa'–which meant water. Her face would light up in a big smile whenever anyone called her name. Her parents took great pride in her, and spoiled her terribly.



But at 10 months Munni got sick. It began like a bad cold, with fever and diarrhea. Munni's mother took her to a doctor in a neighboring town. The doctor gave her an injection in her left backside. A few days later Munni got worse. First her left leg began to hurt her, then her back, and finally both arms and legs. Soon her whole body became very weak. She could not move her left leg at all and the other leg only a little. In a few days the fever and pain went away, but the weakness stayed, especially in her legs. The doctor in town said it was polio, and that her legs would be weak all her lift.

Munni's mother and father were very sad. In those days there was no rehabilitation worker in the village or in the neighboring towns. So Munni's mother and father took care of her as best they could. In time, Munni learned to crawl. But she did not learn to dress or do much for herself. Her parents felt sorry for her, so they did everything for her. She gave them a lot of work.

Then, when Munni was 3 years old, a baby brother was born. This meant her parents had less time for Munni. Her little brother was a strong, happy baby, and her parents seemed to put all their hopes into the new child. They paid less attention to Munni, rarely played with her, and never took her out with them in to the village. Munni had no friends or playmates–except for her baby brother. Yet sometimes, for no clear reason, Munni would pinch her baby brother and make him cry. Because of this, her parents did not let Munni hold or play with him often.

Munni became more and more quiet and unhappy. Remembering how quick and friendly she had been as a baby, her parents sometimes wondered if her mind, too, had been damaged by her illness. Although the doctor had explained that polio weakens only muscles, and never affects a child's mind, they still had their doubts.

When Munni was 6 years old, a third child was born–a baby sister. This seemed to make Munni even more unhappy. She spent most of her time sitting outside behind the hut drawing pictures in the dirt with a broken stick. She drew chickens, donkeys, trees, and flowers. She drew houses, people, waterjugs, and devils with horns and long tails. Actually, she drew remarkably well for a child her age. But no one noticed her drawings. Her mother was busier than ever with the new baby.



Munni was 7 years old when the village school teachers, guided by a health worker from a nearby village, began a CHILD-to-child program in the school. The first and second year children (who were in the same class) studied an activity sheet called "Understanding children with special problems".

Most of the children knew of only one seriously disabled child in their village. This was Pawan. Pawan walked in a jerky way, with crutches. He had one hand that sometimes made strange movements. And he had difficulty speaking clearly, especially when he was excited. But Pawan did not seem to need any special help–or at least not anymore. He was already in the fourth grade of school and doing well. He had lots of friends. He managed to go anywhere and do almost anything for himself, if awkwardly, and nearly everyone treated him with respect. It was easy to forget he was disabled.

Then one little boy remembered. "There's a girl who lives in a house at the far end of the village. She crawls around on her hands and knees, and spends a lot of time just sitting outside. She always looks sad. I don't know her name, but she looks old enough to be in school".

"Let's invite her to come to school with us," said one of the children.

"But how," asked another, "if she can't walk ?"

"We could bring her in a push cart!"

"No! The path from her home is too steep and rocky."

"Then we'll carry her! If we all help, it will be easy."

"Let's go to her house this afternoon." "Good idea!"

That afternoon after school, 6 of the school children, together with their teacher, visited Munni's home. Munni, who was out back, was too shy to come in. So they started talking with her mother.

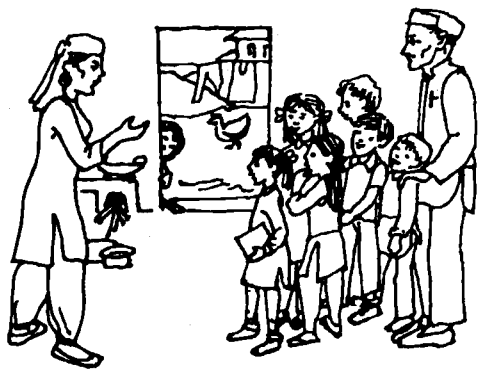
"We want to be her friends," they said. "And to help her go to school."

"But she can't go to school," her mother said with surprise. "She can't even walk!"

"We can carry her," offered the children. "We'll come for her every day and bring her back in the afternoons. It's not far, really!"

"The whole class is ready to help out," said the teacher. "And so am I."

"But you don't understand," said her mother. "Munni's not like other children. They'll tease her. She is so shy she doesn't open her mouth around strangers. And besides, I don't see how school could help her."



The teacher tried his best to explain to the mother the great importance of school for a child like Munni. The children promised that they would all be friendly and help her in any way they could. But her mother just shook her head.

"Do you think Munni would like to go to school ?" asked the teacher.

Her mother gave a tired sigh. Then she turned to Munni, who was hiding outside the door but peeping in at the visitors. "Munni, darling, do you want to go to school ?"

Munni's eyes opened wide with fear. She shook her head in a terrified NO and disappeared behind the doorway.

"There, you see!" said Munni's mother. "For Munni, school just wouldn't make sense....Now I have a lot of work to do, please excuse me. But thank you for thinking of my poor little girl."

"Please give it more thought," said the teacher as he and the children went out the door, "And thank you for your time."

"Have a nice day," said Munni's mother, and went back to work.

At school the next day the teacher met with the whole class to discuss their visit to Munni's home.

"This CHILD-to-child stuff sounds so easy and fun when we pretend," said one of the children. "But when we try to use it in real life, it ain't so easy."

"Isn't!" said the teacher.

"Still," said one little girl who had visited Munni's home, "we have to keep trying. Did you see the way Munni looked at us? She was so scared she was shaking. But she was interested, too. I could tell.

She looked so....lonely!"

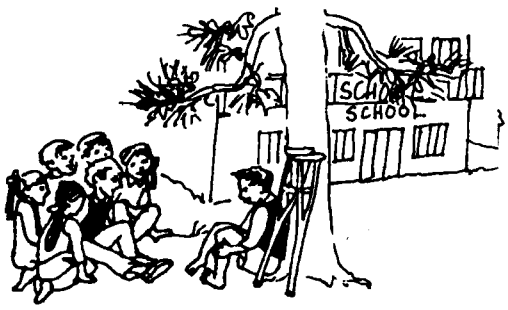
"But what can we do? I don't think her mother wants us to come back."

There was a long silence. Then one little boy said. "I've got an idea! Let's talk to Pawan. He's handicapped, too. But he's in school and is doing fine. May be he can help us."

After school, several of the first and second year students waited for Pawan, who was in the fourth year. They told him about Munni, and what happened when they visited her home.

"How was it when you began school, Pawan?" asked the children. "Were you afraid? Did your parents want you to go? How did the other children treat you?"

Pawan laughed. "One question at a time!" He spoke slowly, with a twisted mouth and a sort of jerky speech that sometimes made him hard to understand. "Help me sit down under that tree." Pawan moved forward on his crutches. The children helped him sit down. (He explained that his hips and legs wanted to stay straight when he wanted to bend them.) He sat leaning against the tree, and began to answer the children's questions.



"Sure, I was afraid to go to school, at first," said Pawan. "And my mom and dad didn't want to send me. They were afraid kids would tease me or that it would be too hard for me. It was grandma who talked us all into it. She said if I couldn't earn my living behind a plow, I'd better learn to earn it using my head. And I intend to."

"What do you want to be when you grow up?"

"May be a health worker," said Pawan. "I want to help other people."

"Did other kids tease you when you started school?"

Pawan frowned. "No...not much. But they didn't know what to do with me, so usually they didn't do anything. They would stare when they thought I wasn't looking. And they would imitate the way I talk when they thought I wasn't listening. But when they thought I was looking and listening, they would pretend I wasn't there. That's what was hardest for me. They never asked me what I thought, or what I could do, or if I wanted to play with them. I felt lonelier when I was with the other children than when I was by myself."

"But now you have lots of friends. You seem like one of the gang. What happened?"

"I don't know," answered Pawan. "The other kids just got used to me, I guess. They began to see that even though I walk and talk funny, I'm not really all that different from them. I think it helps that I do well in school. I like to read. I read everything I can find. Sometimes when kids in my class have trouble reading or understanding something, I help them. I like to do that. At first they gave me the nickname 'Crabfoot' because of how I walk. But now they call me 'Professor' because I help them with their lessons."

"The first nickname was about what's wrong with you," observed one little girl. "And the second is about what's right. I guess you showed them what's most important!"

Pawan mouth twisted into a smile and his legs jerked with pleasure. "Tell me more about Munni," he said.

They told him all they could, and finished by saying, "We tried as hard as we could, but Munni's mother doesn't want her in school and Munni doesn't want to go either. We don't know what to do. Do you have any ideas, Pawan?"

"Maybe if I visit the family–with my parents. They can try to convince her parents, and I'll try to make friends with Munni."

The next Sunday, when Pawan' father was not working in the fields, Pawan asked his parents to go with him to Munni's home. They arrived in the early afternoon. Munni's mother and father, together with the 2 younger children, were all sitting in the shade in front of the hut. Munni's father was sharpening an ax while her mother picked lice from the children's hair. They all looked up in surprise to see the boy on crutches approaching, followed by 2 adults.

The path near the hut was steep and rocky. A few meters from the hut, Pawan tripped and fell. Munni's father ran forward to help.

"Are you hurt?" asked Munni's father, helping him up.

"Oh no," laughed Pawan. "I'm used to falling. I've learned to do it without hurting myself...We've come to talk to you about Munni. These are my parents.

"Come in," said Munni's father. They all exchanged greetings, and everyone went inside.

While Pawan' parents were talking with Munni's parents, Pawan asked if he could speak with Munni.

"She's outside," nodded her mother, pointing to the back doorway. "But she doesn't speak to strangers. She's too afraid."

"She doesn't have to speak if she doesn't want to." said Pawan gently, yet loudly enough so that Munni could hear, if she was listening.

Pawan went out and found Munni bent over a drawing in the dirt. She glanced up at him as he approached, and then looked down at her drawing, but without continuing it.

There were several drawings on the ground of different animals, flowers, people, and monsters. Munni had just been drawing a tree with a big nest in it and some birds.

"Did you draw all these?" asked Pawan. Munni did not answer. Her small body was trembling.

"You draw very well!" said Pawan, admiring and commenting on each of her drawings. "And with just a stick. Have you ever tried drawing with pencil and paper?" No answer. Pawan continued. "I bet that nobody in school can draw this well!" Munni, still staring at the dirt, trembled and said nothing. Pawan also was silent for a moment. Then he said. "I wish I could draw like you do. Who taught you?"

Munni slowly lifted her head up and looked at

Pawan, or at least at his lower half. She looked first at his turned–in–feet and the tips of his crutches. Then she looked at his knees, which had dark calluses on their inner sides where they rubbed together when he walked.

"Why do you walk with those sticks?" she asked.

"It's the only way I can," he said. "My legs don't like to do what I tell them."

Munni lifted her head and looked up into Pawan' face. Pawan tried to smile, but knew his mouth was twisting strangely to one side.

"And why do you talk funny?" asked Munni.

"Because my mouth and lips don't always do what I want either," said Pawan. And it seemed he had even more trouble speaking clearly than usual.

Munni stared at him. "Do you really like my drawing?"

"I do," said Pawan, glad to change the subject. "You have a real gift. Real talent. You should study art. I'll bet some day you could be a great artist."

"No," said Munni, shaking her head. "I'll never be anything. I can't even walk. Look!" She pointed to her small floppy legs." They're even worse than yours!"

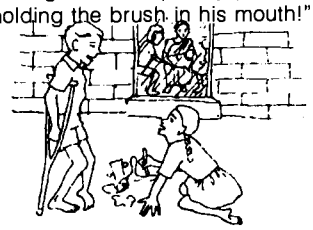
"But you draw with your hands, not your feet!" exclaimed Pawan.

Munni laughed. "You're funny! she said. "What's your name?"

"Pawan."

"Mine's Munni. Do you really think I could be an artist ?-No, you're only joking. I'll never be anything. Everybody knows that!"

"But I'm not joking, Munni," said Pawan. "I read in a magazine about an artist who paints birds. People come from all over the world to buy his pictures. And you know something, Munni, his arms and legs are completely paralyzed. He paints holding the brush in his mouth!"



"How does he get around?" asked Munni.

"I don't know," said Pawan. "People help him, I guess. But he does get around. The magazine said he has been to several countries."

Munni said, "Wow! Do you really think I could become an artist?"

Pawan looked again at the drawings in the dirt and truly wished he could draw as well. "I know you could!" he answered.

"How do I start?" asked Munni, sitting up eagerly.

"First," said Pawan, "you should probably go to school."

"But how?" said Munni, looking at her legs.

"That's easy," said Pawan. "All the school children want to help. But you have to want to go."

"I...I'm afraid..."said Munni. "Do you go to school, Pawan?"

"Yes, of course," he answered.

"Then I want to go, too!"

Inside the house, Pawan' parents were trying to convince Munni's parents of the importance of sending her to school. They explained how they had the same doubts about Pawan, and how much school had helped him.

"It's not only what he is learning that's important," said Pawan' mother, "but what it has done for him personally. He has more confidence a whole new view of himself."

"And we've come to look at him differently, too," said Pawan' father. "He's a good student-one of the leaders in his class!"

Munni's father coughed. "Even if all you say is true. Munni doesn't want to go. She's afraid. You see, the same illness affected her...."

His sentence was cut off by Munni, who came bursting in the back doorway on hands and knees. "Mama! Papa!" she shouted. "Can I go to school? Will you let me? Pleeeeease?"

Her father's mouth fell open for a moment. And then he smiled.

The next day Munni began school. The other children learned from Pawan that Munni was ready to go, and they worked hard Sunday evening making a 'sitting stretcher' for her. One of the children had seen a similar stretcher when an injured man had been carried down from the high mountains. It was a simple wooden chair, tied firmly between two poles. The children finished making it by sunset and the next morning arrived with it at Munni's house. Pawan went with them to give Munni courage. He was so excited that he fell 3 times!

Munni was so frightened when she saw the children that she almost decided not to go. But when they brought her special chair to the door, she lifted herself onto it with her strong arms. And before she knew it, she was on her way -to school!



The first day of school went well. Everything was so new, and the children were all so friendly, that Munni almost forgot she was afraid. On the way home, she smiled and laughed as the children carried her.

Six months have now passed since Munni started school. Although she began 2 months late, she is already able to read and write letters and words as well as most of her classmates. But drawing is what she likes most. The other children often ask her to draw pictures for them.

Munni has made many friends. The children in her class who first looked at her as someone 'special', have now accepted her as one of their group. They include her in many games and activities, and treat her as just another child.

Some problems have arisen. At first, carrying Munni to and from school each day was fun. But after awhile, many of the children got lazy and stopped helping. This meant more work for those who were left.

The children got a new idea and asked their fathers for help. One Sunday a group of about 15 men and 20 children worked on improving the steep path from Munni's house to the main walkway leading to school. They made the curves wider so that the trail would be less steep, removed all rocks, leveled the surface, and pounded the dirt into a hard, smooth surface.

One of the children's father had a small repair shop in the village. Another was a carpenter. With the help of their children, these 2 craftsmen made a simple wheelchair out of an old chair, 2 casters, and some bicycle wheels.

Munni was excited when she saw the wheelchair. Her arms and hands were already strong, and with the little practice she learned to wheel her new chair up the long winding trail to the village.

"Now you can come and go to school on your own," said Pawan. "How do you feel?"

"Free!" laughed Munni, "I feel like writing a declaration of independence!" Then she thought a moment and frowned, "I know I'm not completely independent–but that's all right. We all depend on each other in some ways. And I guess that's how it should be."

"Its being equal that counts," said Pawan. "It's knowing that you're worth just as much as anybody else. Nobody's perfect!"

Things also began to go better at home. As Munni's self–respect grew, so did her parents' appreciation of her. Suddenly both Munni and her mother realized that there were many things that Munni could do. She began to help with preparing meals, washing clothes, and taking care of her younger brother and sister. She treated them more lovingly and never pinched or made them cry (except, of course, when they deserved it!).

Munni's mother wondered how she had ever managed to get along without Munni's help. She missed her during the long hours she was at school. And when she realized she was going to have another baby, she thought Munni would have to stop going to school to help more at home.

Munni's father shook his head. "No," he said. "School is more important for Munni than for any of our other children-if she is going to learn skills to make something of her life. "And besides," he reminded his wife, "if we hadn't sent her to school, she would probably still be sitting outside in the dirt. It took the schoolchildren to teach *us* what a wonderful little girl we have."

Munni's mother smiled and nodded in agreement. "You're absolutely right," she said. "The school children...and especially that wise little boy. Pawan!"



CHILD–to–child ACTIVITY:
CHILDREN WHO HAVE DIFFICULTY UNDERSTANDING



In many communities, a child who is ***mentally*** slow, or ***retarded***, has an especially difficult time. Other children may make fun of him for not being as quick as they are, or for 'not being able to understand, follow, or remember things as easily as they can. They may not realize that this child has the same need for friendship, play, and respect as they do.

This activity is designed to help children gain more appreciation of both the needs and possibilities of the child who is mentally slow. They will explore possible ways to help the child to feel a part of their group, and to learn new things at his or her own speed.

Talk with the children

You may want to start the activity by asking the children questions such as:

- Do you know a child who doesn't seem to understand or remember things as well as others her age?
- Does this child play much with other children?
- How do other children treat this child?
- How do you think it would feel if you had a similar difficulty?

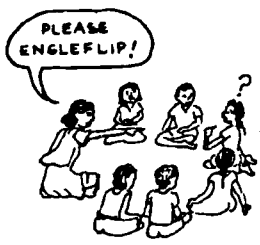
Games and activities

Begin with games and activities that help the children discover what it may feel like to have difficulty understanding, and to be unfairly blamed for that difficulty. Then the children can look for ways to help a person learn that are easier, friendlier, and more effective.

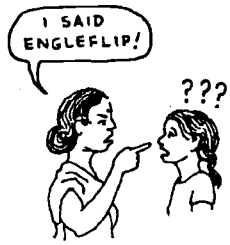
A GAME TO START WITH: "ENGLEFLIP"

("Engleflip" is a nonsense word, but let us pretend that it means 'Stand up'.)

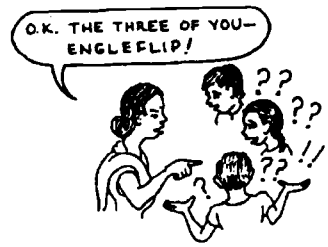
1. Ask one child in the group to 'engleflip'.



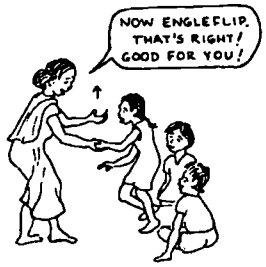
2. Say it louder. Get angry.



3. Ask several other children.



4. Now help the children understand what you mean by showing them, assisting them, or gently explaining.



After the activity, discuss . . .

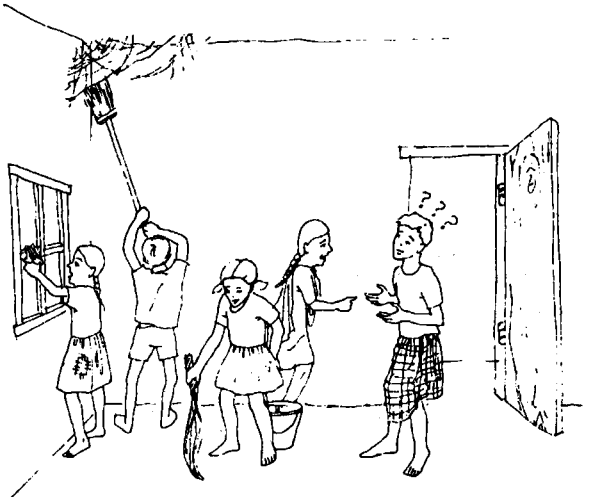
- How did you feel when you could not understand the teacher?
- Was it right for the teacher to get angry? Did it help?
- Did the teacher finally do it better? In what ways?
- In what ways might your difficulty with 'engleflip' be similar to that of a child who has trouble understanding things?

Role playing

You can also use role plays or skits to explore the difficulties of a child who does not understand, and how to help him understand. For example.

Ask 5 children to put on the role play.

They can pretend to be cleaning house. But before they start, ask one child to go out of the room. Tell the other 4 that after they have cleaned for awhile, they should turn to the 5th child and say, "Blah, blah, blah, blah." Tell the 4 children that this means, "Go get some water." But the 5th child will not know this.



Tell the 4 children to keep saying the words, and then to add other ways to help the 5th child understand.

The 5th child comes back and they begin.

Divide the class in groups of 5 (or more) and repeat the game. Have the children think of different situations and different meanings for "Blah, blah, blah, blah."

Afterwards, discuss with the whole class:

- How did the child feel who did not understand?
- How did the others feel?
- What did the others do to help the child understand?
- What else could they have done?

Follow-up activity: Write or tell a story

The story might begin by one child waking up one morning and not understanding anything anyone says.

Each child in the class writes or tells the rest of the story in his and her own way. Invite them to draws pictures with their stories.

Ask the children to include in their stories ideas for helping the child understand.



This activity could be done in a language or writing class. After they have written the stories, the children can read them to classes of younger children.

Memory

It is important that the children also realize the importance of remembering things and the difficulties of a child who has an especially hard time remembering. Then they can try to find ways to help that child remember things more easily.

MEMORY GAME # 1

Ask the children to do many things, one after the other. Say the list of things in one sentence, very quickly. Do not wait for the children to do each thing before you say the next.

If the children cannot remember all the things, repeat the list louder, but just as fast.

Now do it differently. Say each thing slowly, and wait until they do one thing before you go on to the next.





MEMORY GAME #2

Place 14 different things on a table where the children can see them. Let them look at them while you count to 30. Then cover them with a cloth and take 7 things away. Remove the cloth. Have the children write down the things that are missing.

Repeat the game using 6 different things and removing 3. Which is easier ?

After the memory games:

- Ask the children why it was easier the second way.
- Explain that children who have trouble understanding are often confused when they are given too many instructions at once. Even 2 instructions at once may be too many for such a child. What suggestions do the children have?
- If the children know a child who has a hard time remembering things, they can help her improve her memory by playing these same kinds of games with her. Start with only 2 or 3 words or things, and as the child's memory begins to get better, gradually add more. Each time the child does well, praise her or give her a prize.

STORY AND DISCUSSION: "I FORGOT"

Begin to tell a story about a little boy whose mother asks him to go to the corner store and buy some bananas. He comes back with nothing.





- Why did he not bring the bananas ?
- What might have happened ?
- How could we help ?

Another day the boy goes to buy bananas and comes back with matches. Why? How could we help him remember? Here are some possibilities:

- Another child could go with the boy-not to buy the bananas, but to help him remember, or give him 'clues'.
- He could take a picture to remind him-or sticks to remind him of the number. *Another child could practice with him at home. Play remembering games. Start with one thing at a time.
- **Praise or reward the boy each time he remembers and does it right.** Do not praise and **never punish** the child when he forgets. Remember: He has difficulty remembering. It is not his fault!

ROLE PLAY-GOING SHOPPING

The children can act out a role play something like this.

A mother sends her child shopping. She tells him a long list of things he must buy. He goes around the class 3 times and meets a lot of people who ask him a lot of questions like "What time is it?" "Where are you going?" "Which way is the market?"

How much does the child remember when he gets to the store?



Talk with the class about what happened. How might it be made easier for the child to remember what he must buy? (Let us suppose the child cannot read.)

PUTTING INTO PRACTICE WHAT WE LEARN

Do the children know any child in the village or neighborhood who has difficulty understanding or remembering?

Is there something they can do that might help the child to:

- feel he has friends who respect him and with whom he can play?
- remember things better?
- learn to do more for himself?
- go to school, and get the extra help he needs?
- enjoy himself more and fit into the community better?

If there are some children (or grown-ups) in town who make fun of the disabled child or treat him badly, is there anything the children can do? What? What precautions should they take? The story on the next page can give children ideas for helping a child who is mentally slow to learn basic skills. For more ideas, see Chapters 32 to 42.

ZAKI AND NASIR
Story From Pakistan

This is the story of 2 brothers, Zaki age 9, and Nasir age 7. Their father was a shopkeeper in Peshawar, and their mother was a teacher. They had a big brother and big sister who were both students, living away from home. Zaki was doing well at school but Nasir had never even started school. There was something different about Nasir from other children. Nasir was mentally disabled. His brain did not work properly. He could only say a few odd words. He could not dress himself, and he made a mess at mealtimes.

Zaki felt ashamed to have such a brother. Neighborhood children made fun of Nasir. They called him nasty names and pushed him about. Nasir would get angry and try to hit them, and then fall flat on his face. Some of the grown-ups would shake their heads and say Nasir had an evil spirit inside him.

The worst of it for Zaki was that he had to take care of Nasir a lot of the time, when there was nobody else at home. It meant that he could not go out to play with his friends from school. And there was nothing to enjoy in looking after Nasir. He could not talk. He did not know how to play any games.

Zaki felt very sorry for himself, and used to hate Nasir for the times he had to stay in the house looking after him. It was so unfair! He had never done anything wrong, so why should he have to have a brother like that, who stopped him from going out and playing with his friends?

One day a visitor came by their house, looking for Zaki's father. It was his cousin, Dr. Daud. Zaki's parents were out. Only Zaki and Nasir were in the house. Dr. Daud noticed that Zaki had been crying. "What's the matter?" he asked Zaki told Dr. Daud all about his brother Nasir and how his own life was spoiled by having to look after him.

Dr. Daud listened carefully. Then he said, "Yes, you've certainly got a problem. But tell me, what are you doing about it?" "What can I do?" cried Zaki. "Nasir's just as bad now as he was 2 years ago, and he'll be twice as stupid in another 2 years time." Dr. Daud looked thoughtful. "Well, he might be," he replied. "But that depends on how clever ***you*** are."



"What do you mean?" asked Zaki. "I'm getting good marks at school, while ***he*** can't even start." "Well," said Dr. Daud, "if you're clever enough for 2 then you could really help Nasir to change for the better. Then you'd both be happier and you'd get more free time to go out and play." "How can I do that?" asked Zaki. Dr. Daud said "First, I'll have a talk with your father and mother."

That evening Dr. Daud called again and had a long talk with Zaki's parents. "I can't give you any medicine for Nasir," he said. "because there isn't any that will cure him of mental disability. Not even the best surgeons can do anything. But you have the answer right here in your own home. If you have enough time and patience you can teach Nasir to do a lot more than he can do now." But Zaki's father said, "That's just the problem! We don't have enough time at home. I can't have Nasir in the shop. He pulls everything off the shelves. And his mother is teaching at school and then has to get our food, and then gives private lessons. We can't stop working, or we'll never eat and pay the rent."

"But Zaki has the time," said Dr. Daud. "He could do a lot to teach Nasir. Why not try it for a month. I'll show you where to start."

So Zaki became Nasir's teacher. But he also learned a lot of things himself. He started teaching Nasir to dress himself. Of course, Zaki knew how to put on a shirt. You just pick it up, and put it on! But he soon realized that there was more to it, when teaching Nasir. First you had to find which was the back and which was the front of the shirt. Then you had to find the main hole and get the head through it. Then one arm went into the right sleeve. Then the other arm into the other sleeve. Next you pull the whole thing down over yourself.

Then there was teaching Nasir to feed himself. You would think it was obvious, how to eat! But Nasir had to find out step by step how to pick up a piece of chapati, get some curry on it, put it into his mouth and remember to chew and swallow. It took dozens of repetitions and lots of encouragement and rewards before Nasir learned each step. Zaki began to realize what Dr. Daud had meant. He needed to be clever enough for 2 in order to puzzle out how to teach Nasir. But when Nasir succeeded in some small step, they were both so delighted that it made all the effort worthwhile.

A few months later Dr Daud was passing Zaki's house. Zaki came rushing out. "Quick, Doctor, you must come in!." Dr. Daud hurried in, thinking he would find someone at the point of death. But all he saw was Nasir, grinning broadly in his chair. "What is it? What's the matter?" demanded the doctor. Zaki was so excited he could hardly speak. "He said a whole sentence, Doctor Nasir did. He's never said more than 2 words together before now. He just said 'Zaki give sweets to Nasir' I've been trying for months to get him talking. He did it! He did it!"

Dr. Daud smiled. "I think you like your brother better than you used to," he said.



CHILD-to-child ACTIVITY:

LET'S FIND OUT HOW WELL CHILDREN SEE AND HEAR



Background discussion

Some children cannot see or hear as well as other children. Often we do not know about this and the child says nothing. But because the child does not hear the teacher or see the blackboard, he may not learn as quickly as others. So he may try to hide in a corner. **We can help him by letting him sit close to the teacher.**

Also, babies who cannot hear well do not learn to talk or understand as early as others.

In this activity, the school children try to find out which young children and babies do not see or hear well, and need help.

HELPING CHILDREN UNDERSTAND THE PROBLEM

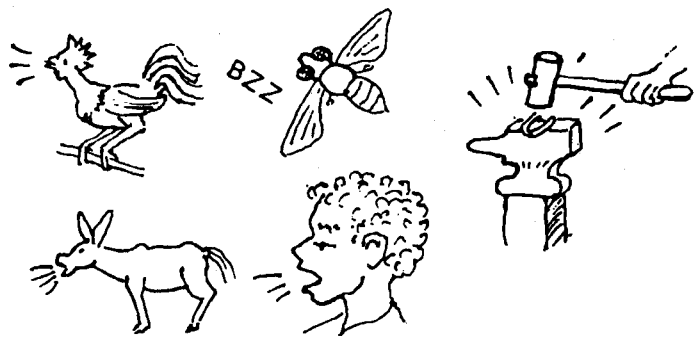
One way to get children thinking about these problems is to ask questions like:

- Do you know anybody who does not see or hear well?
- Do you act differently with these people? Why?
- How would you feel if you did not see well? Or hear well?

Games to help children understand *the difficulties of poor hearing*

GAME: LISTEN LISTEN

All the children are completely silent for 3 minutes. They listen very carefully to the noises around them. Afterwards, they write down or draw everything they heard.



GAME: WHAT DID YOU SAY?

One child plugs his ears while another tells a funny story to the group. Then one of the children plays 'teacher' and asks everyone, including the child who had his ears plugged, to answer questions about the story. Finally, they ask him what it felt like, not being able to hear the story well.

Ask the children what they can do to help a child to hear better. Their suggestions might include:

- Have the child sit 'up front' close to the teacher.
- Everyone can take care to **speak slow, clear,** and **loud** (but do not shout).
- **Use gestures or 'sign language'** (if the child hears very little or not at all).
- Watch people's mouths and try to understand what they say. This not easy if you do not hear the words. Have the children try it.

GAME: TALKING WITHOUT WORDS

Children who hear very poorly or not at all often cannot speak. This is not because they are stupid, but because they need to be able to hear in order to learn how to speak. This game will help children appreciate the difficulties of a child who cannot speak, and give the children ideas of how to 'talk' without words to a child who does not hear.



Play a game where someone explains something to others through acting ***only***, without words. The others must guess what it is he is trying to say. The leader can start by acting out a simple phrase like: "I want a glass of water." The children try to guess what the leader is doing. Next have the children take turns acting out different things and ideas. Start with easy phrases like:

- I want to go to sleep.
- Give me the ball

And work toward more difficult ideas like:

- I'm lost and can't find my house.
- I had a bad dream.

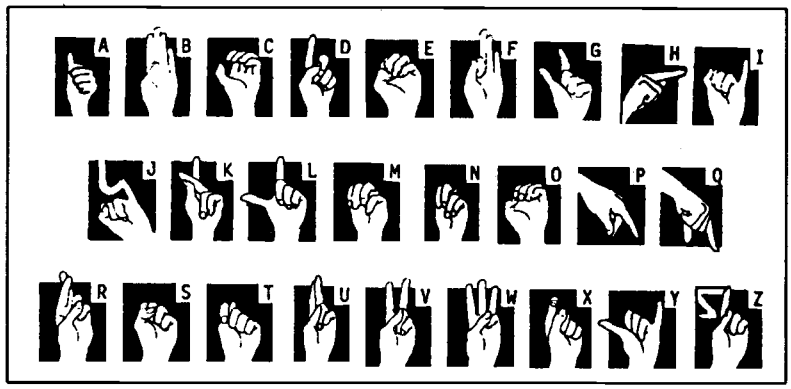


Discussion after the game:

- Was it difficult to explain something without talking?
- How did you feel when no one understood you?
- What did the other children do to help you tell them what you wanted to?
- Could they have done more? What?
- How might you help children who cannot speak to communicate?

Explain to the children about **sign language for the deaf.** This is like the game in which children 'talk' with their hands. One form of sign language uses mostly the alphabet. Another form, which deaf persons prefer for 'talking' with each other, uses symbols for different actions and things.

If there is a deaf child in the school, or in the village or neighborhood, perhaps the children would be interested in finding a way to help that child learn to 'sign'. Or they may want to learn themselves, in order to be able to 'talk' with the deaf child.



Alphabet sign language used in the USA. More discussion of sign language is on p. 320.

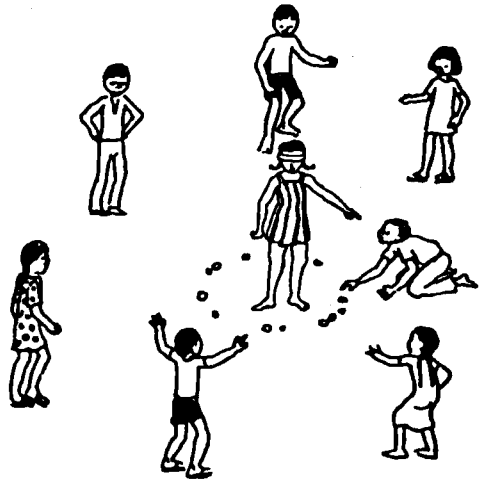
If 1 or 2 children in the class can learn to sign and then help translate spoken language into sign language, this can allow the deaf children to learn and take part more fully in the school and in the community. (For books to learn sign language, see p. 771–772). Also see Chapter 31.

Games to help children understand *the difficulties of poor sight*

GAME: CATCH A THIEF

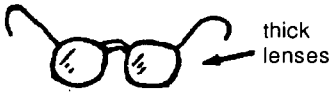
This game can help children understand both the **importance of good hearing** and the **difficulties of not seeing.**

- The children form a circle. One child stands in the middle with her eyes covered. Around her feet are small stones, nuts, or other small objects.
- The other children, one by one, try to creep up and steal these things.
- If the child in the middle hears the 'thief', she points to him and he is out of the game.
- The goal is to see who can steal the most objects without being heard.

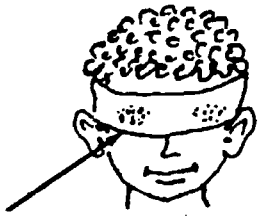


GAME: BLURRED VISION

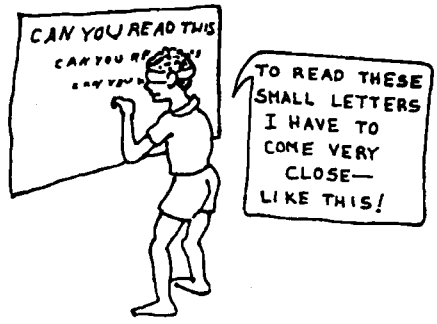
One or more children are temporarily given poor or blurred vision in one of several ways:



Put somebody's *powerful* eyeglasses on a child who needs no glasses.



Or, cover his eyes with a piece of tracing paper, wax paper, or other material that you can see through slightly.



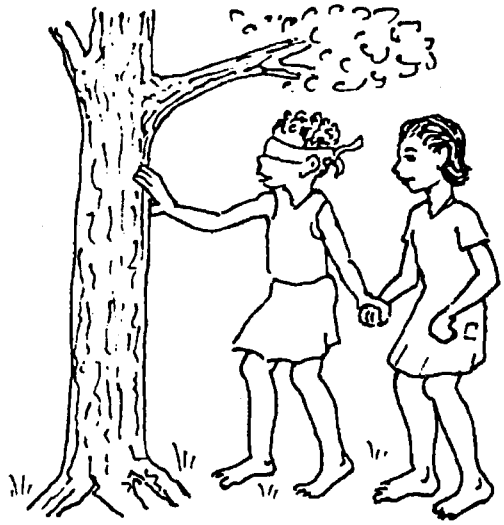
Have the child try to read from a book with letters of different sizes. Do the same on the blackboard. What trouble does he have? How close does he have to get? Does he read aloud from his book as well as the other children?

GAME: BLINDFOLDED PARTNERS

The children are in pairs. One is blindfolded, the other is her guide. The guide takes the blindfolded person for a walk, letting her feel different things and taking care of her.

After the game, discuss:

- How did it feel not to be able to see?
- What did your guide do that was helpful? What might she have done better?
- Did you trust your guide?

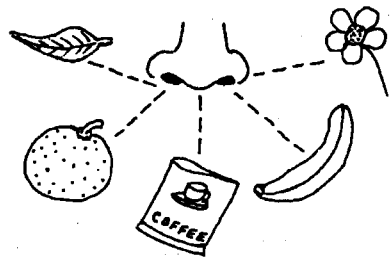


GAME: FEEL A FRIEND



One child is blindfolded. He tries to recognize his friends by feeling them.

Similar feeling games can be played trying to identify different things by feeling them.



GAME: WHAT'S THE SMELL?

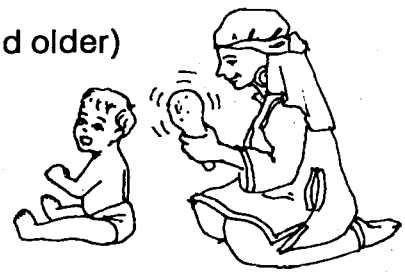
Blindfold the children and have them identify things by their smell: things such as orange, tea leaves, banana, and local herbs.

After the children play these different games, explain to them that because **blind people** cannot see, they **often develop outstanding ability to identify things through hearing them, feeling them, and smelling them.**

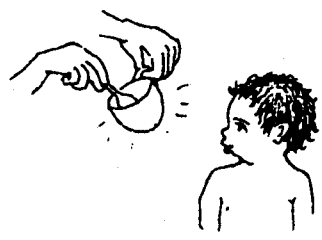
FINDING OUT WHICH CHILDREN HAVE PROBLEMS WITH HEARING AND SEEING

It is important to find out **as early as possible** if a child cannot hear or see well. Older children can do some simple tests with their baby brothers and sisters. A class or group of children can also test the seeing and hearing of younger children, such as those in nursery school or the first year of elementary school.

Testing the hearing of babies (4 months old and older)



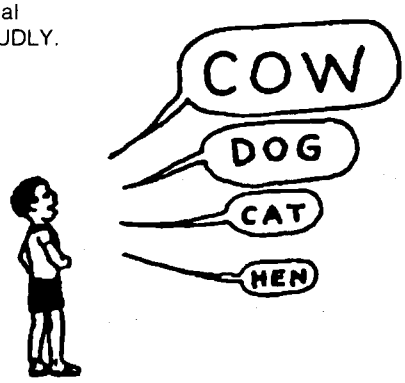
- Children can notice if their baby sister responds to different sounds, high and low, loud and soft. The baby may show surprise, make some movement, or turn her eyes or head toward the sound. Notice if the baby responds to her mother's voice when the baby does not see her.
- Or make a rattle from seeds or small stones. Creep up and shake it behind the baby's head, first on one side and then the other. See if the baby is surprised.
- Then call the baby's name from different places in the room. See if the baby responds.
- To test if a baby hears some kinds of sound but not others, do this. Sit at arm's length from the baby, and to one side. When she is not looking, make different kinds of sounds. Say "Ps" and "Fth" to test for high-pitched sounds, then "Oooo" for low-pitched sounds. For other high-pitched sounds, crinkle a thin, stiff piece of paper or rub a spoon inside a cup. For other low-pitched sounds, watch if the child notices the noise of a passing truck, a train whistle, a cow's "moo", or low notes on a musical instrument or drum.

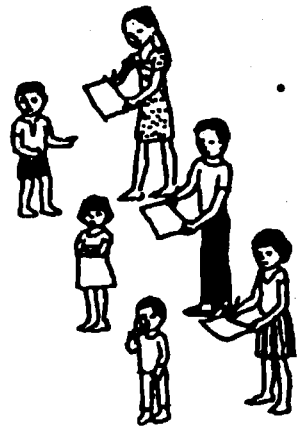


If the baby does not show surprise or turn her head with any of these sounds, she may have a severe hearing problem. If she responds only to certain sounds, but not to others, she has some hearing. But she may not be able to understand language well because she cannot tell certain words apart. As a result, she may not speak as early or as clearly as other children and will need special help. (See Chapter 31.)

Testing the hearing of young children (a game)

- An older child stands several meters from a line of younger children.
- Behind each young child stands an older child with pencil and paper.
- The first child says the name of an animal VERY LOUDLY.





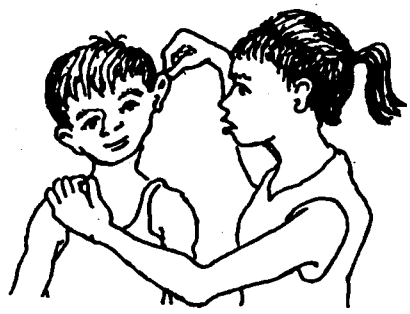
- The young children whisper the word to their older partners.
- The older children write it down.
- Then the first child names other animals, each in a softer and softer voice, until he is whispering.
- After about 10 animals have been named, and the words that the younger children heard have been written down, compare the different children's lists.
- Repeat this 2 or 3 times.
- Any child who has not heard as many words as the others, or has not heard them correctly, probably has a hearing problem.

What to do for the child with a hearing problem

- Let the child sit at the front of the class where he can hear better.
- Be sure everyone speaks clearly and loudly enough. But **do not shout** because shouting makes the words less clear. Check often to make sure the child understands.
- Have one child who hears well sit next to the one who hears poorly-to repeat and explain things if necessary.
- Always try to look at the child while you are speaking to him.
- If possible, the child should be examined by a health worker-especially if he has pus in an ear or frequent earache.

HOW CAN CHILDREN HELP CARE FOR THEIR BROTHERS' AND SISTERS' EARS?

They can regularly look to be sure that there is no pus or small objects inside. If they see anything wrong they should tell an older person, who should take the child to a health worker.



HEARING GAMES THAT CHILDREN CAN PLAY WITH BABIES

Most babies who are 'deaf' hear something. They need help in learning to listen. The children may think of games to help babies listen and learn.

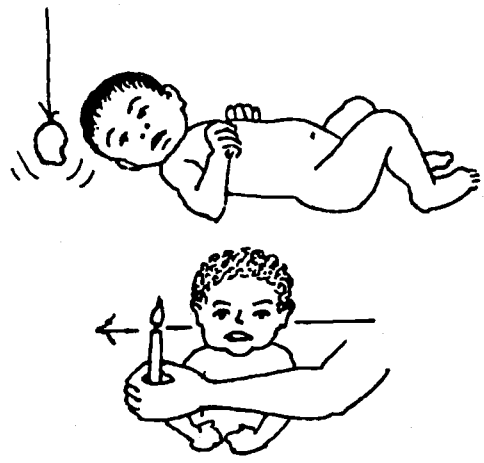


For example:

- Sing to babies, and teach songs to young children.
- Tell them stories and change voices to sound like different people in the story–loud, soft, angry.

Testing if a baby sees (for a child over 3 months old)

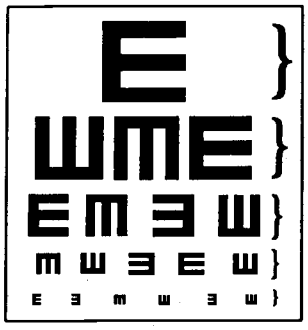
- Children can notice if the baby begins to look at things held in front of him, to follow them with his eyes, to smile at mother's face, and later to reach for things held out to him.
- Hang a bright colored object in front of the baby's face and move it from side to side. Does the baby follow with his eyes or head?
- If not, in a fairly dark room, move a lighted candle or torch (flashlight) in front of the child's face. Repeat 2 or 3 times.

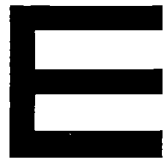


If the baby does not follow the object or light with his eyes or head, probably he does not see. He will need special help in learning to do things and move about without seeing. Other children can help.(See Chapter 30.)

Testing how well children see (4 years old and older)

A group of older children can make an eye chart. They can cut out black 'E's of different sizes and paste them on white cardboard.





Also make one large 'E' shape out of cardboard or other material.



Children making an eye chart. (Mexico)

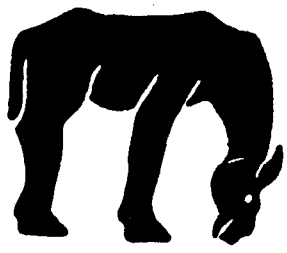
First let the children test each other. Hang the chart in a place where the light is good. Then make a line about 6 meters from the chart. The child to be tested stands behind the line, holding the cut–out 'E'. Another child points at different 'E's, starting from the top.

Ask the child being tested to hold the cut–out 'E' so that its 'leg' point the same way as the 'E' on the chart.

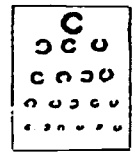
If the child can easily see the 'E's' on the bottom line, he sees well. **If he has trouble seeing the second or third line, he sees poorly.**



- To make the testing more fun, you can use horses in the shape of 'E's.
- Make 5 cards using different size horses. Make the sizes the same as those shown for the letter 'E' in the chart at the top of this page.

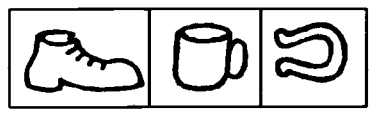


- Or use a chart with C's. Ask the child either to hold a horse shoe in the same position as the different 'c's on the chart, or to tell you for each 'C' which way the horse shoe is going.





To test children who are mentally slow, deaf, or have trouble communicating, you can use pictures of different things they recognize. Hold up one picture at a time and have the child either name it or point to a similar picture– or the real object. For example, you can make a set of cards with pictures like this.



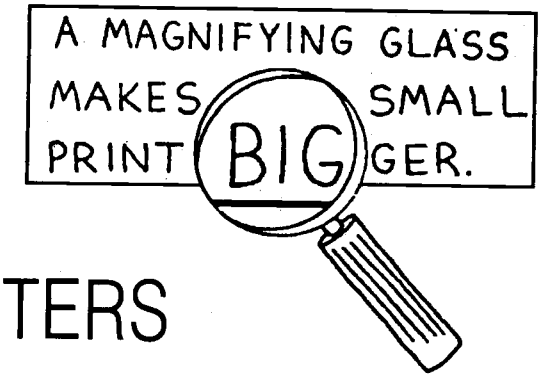




After the children practice testing each other, they can test the eyesight of those in the younger grades and the children who will be starting school soon.

WHAT TO DO FOR THE CHILD WHO SEES POORLY

- Be sure he sits in front, close to the blackboard.
- Write large and dark on the blackboard, and check often to make sure he can read what is there.
- If possible, the child should go to a health worker for more tests. He may need glasses.
- If he cannot get glasses, try to find a magnifying glass. This may help him read small letters.
- If he has not learned to read and write because he does not see well, teach him with



EXTRA BIG LETTERS

- If the child still has trouble reading, have another child read his books and lessons to him aloud.

Looking at each other's eyes for signs of problems

Start with questions to get the children interested. For example:

- Are your eyes the same as your classmates? Shiny? Clear?
- How about the eyes of your younger brother's and sisters?
- Can you see well in the dark? Or do you often stumble at night?
- Do a child's eyes look dull? Are there any unusual spots or wrinkles? If so, see a health worker.



Many children in different parts of the world become blind because they do not eat foods that make their eyes healthy. **Eating yellow fruits or dark green leafy vegetable helps protect the eyes.** Some extra cooking oil added to food also helps.





If children's eyes are red or sore, you can suggest that they wash them often with clean water with a little salt in it (no saltier than tears). This may help eyes get better and keep the flies away. If they do not get better soon, see a health worker.

For more information on eye problems and blindness, see Chapter30.

CHAPTER **49**

Popular Theater

Voluntary agencies, people working in the field of disability or those who are disabled themselves have often found that it is not enough to work towards creating services. Community participation, greater information about disability and all its aspects, in particular attitudes towards the disabled are some areas in which they get involved.

Community theater can be an excellent way to raise awareness about specific needs of disabled persons or to gain greater participation of local people in a community ***rehabilitation*** program. It is also a good method for educating people about important preventive measures. Actors can be disabled persons, parents of disabled children, health workers, rehabilitation workers, school-children, or any combination of these.

No special place is needed. However, some sort of raised area is helpful, with a plain wall or curtain behind. But effective popular theatre has also been carried out in the street, the village square, the marketplace or a courtyard (Angan).

The actors, performers and singers can be found in every community. Nothing more than amateur talent and lots of enthusiasm is necessary for putting together an effective show. Most parts of our country have their own specific traditions of performing arts. It is quite easy to adapt them to ones needs.

Here is an example of how a Voluntary organisation, Jan Madhyam (Delhi) specializing in media based education about disability have adapted a variety of traditional media.

PUPPETRY

To communicate the idea of potential in a person with mental handicap and the importance of training they put together a puppet play called 'Guddi Ko Rehene Do' (leave Guddi alone). The simple story can be performed with any traditional puppets available in your area with large puppets for a large audience or simple glove puppets put together with waste material. This particular story talks about attitudes of the family and community, in particular towards the girl child with mental handicap.

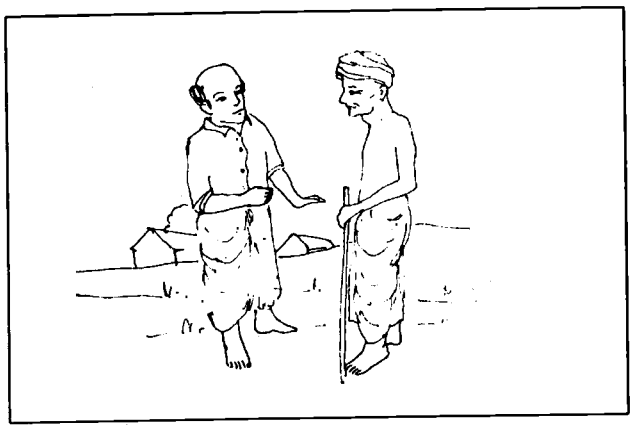


GUDDI KO RAHENE DO

This story talks about attitudes – of the family and the community towards a girl child with mental handicap.

Everyone is looking forward to the wedding festivities. So is Guddi. Like everyone else she wants to play, wear new clothes and look pretty. But her family and the children in her neighborhood feel that she cannot play with them and that she does not need good clothes. Guddi is a burden even to her mother. The Sutradhar, (a family friend) takes her grandfather, who is the head of the family, in confidence and talks to him about Guddi.





Sutradhar : "Why have you given up without trying"?

Grandfather : "We have tried doing everything to help her. We have taken her to temples and priests; to doctors; have given her medicines and injections. We have even made her fast in the hope that she will be cured.

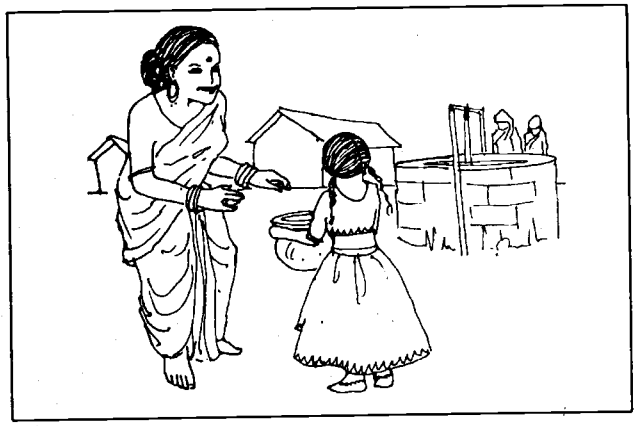
Sutradhar : "Wait a minute Kaka I am not talking about cures. There are none. She can be trained to learn skills to become independent to some extent. Otherwise someone will have to comb her hair even in her old age.

Grandfather (astounded) : "You mean she can learn"?

Sutradhar : "Of course. Mind you it will be hard work for all of you but you owe it to yourselves to try–".

The mother too meets a helpful neighbor and a transformation takes place.

The end of this simple story shows Guddi as a happy and well dressed child, popular with the neighborhood children and a great help to her mother at home.



The Katha Peti from Orissa

Just like puppets which exist in many parts of the country a Katha Peti may also exist in your village. A Katha Peti is a wooden box (it can also be made from cardboard). Every side of this box has brightly painted scenes from stories about Gods and Goddesses. As the story teller and assistant explain the story in songs and words, the sides of the box open out and the story unfolds.

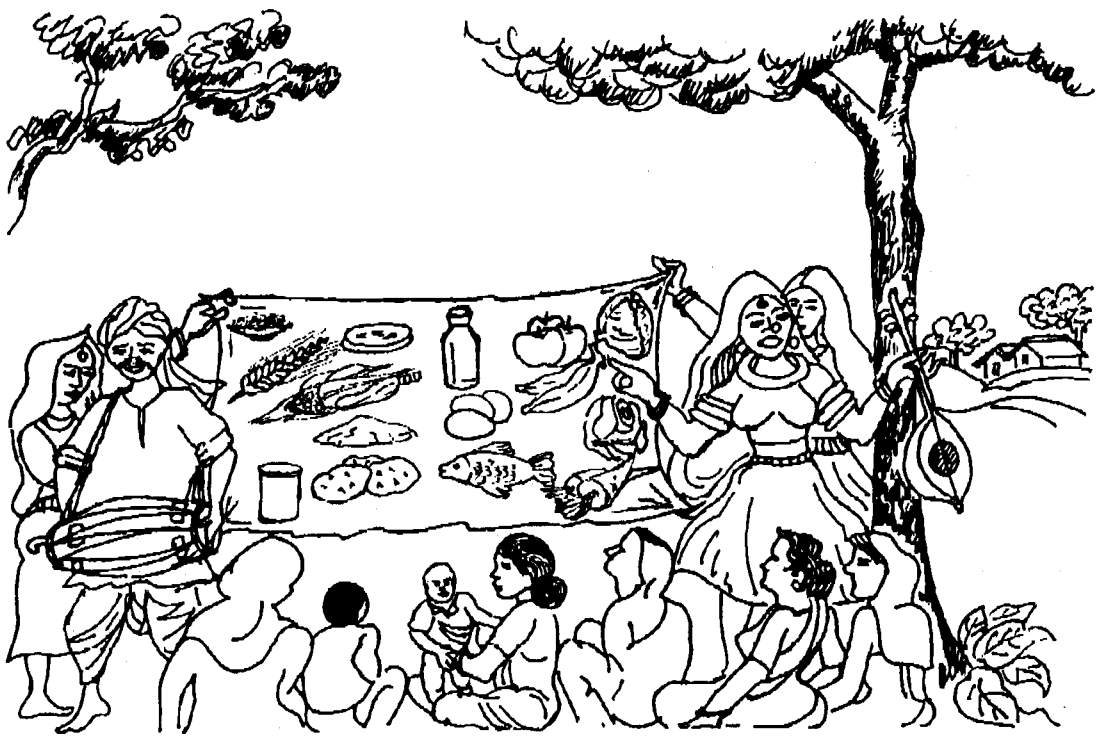
This is an excellent medium for small groups of thirty to fifty people. Here is an example of how the Katha Peti has been adapted to tell the tale of a mother, Puspa who began her married life with many dreams and ambitions. Time passed, and after three daughters at last a son was born, but he was mentally retarded. "It is all your fault", the mother-in-law said and threw her out of the house.

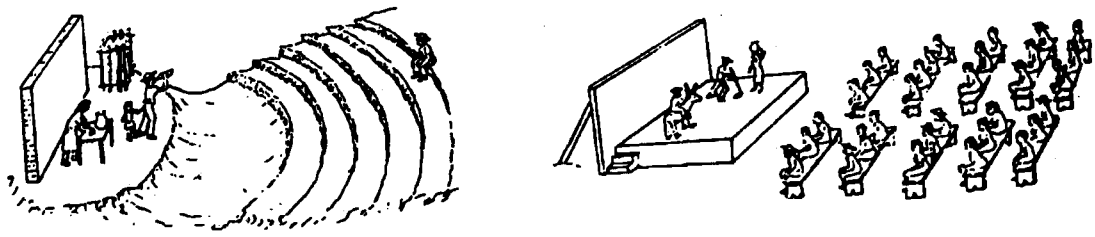
Despondent and unhappy, she lived as a burden in her father's home. A chance meeting with a childhood friend opened the door for a new and hopeful future. Yes, her child was mentally retarded, but he would learn and some day stand on his own feet. The two friend worked hard with a home intervention programme and a new life began for Pushpa and her son.

The Phad from Rajasthan

This is another traditional medium of folk entertainment which is effective and easy to adapt. The Bhopas (travelling performers) of Rajasthan travel from village to village with their Phad (stories painted on scrolls of cloth) singing the story in a silting voice to the rhythm of a drum which a baton is pointed to the pictures which illustrate the story.

Every community has its own traditional media. Using these media stories can be made up to suit the needs of the community.



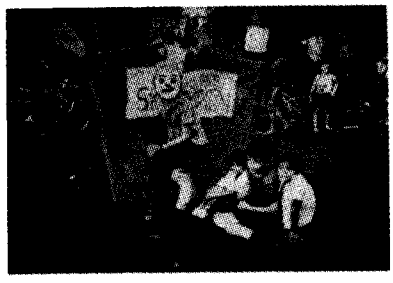


Simple outdoor stages for popular theatre.



The Measles Monster street theater skit in Nicaragua. The Head of the monster is a mask painted on heavy paper, glued to a cardboard carton.

For example, ***measles*** is especially dangerous to poorly nourished children, leaving many with blindness, deafness, fits, retardation, or cerebral palsy. Preventing measles helps prevent disability. In Nicaragua a group of health workers and local children put on a street theater skit called ***'The Measles Monster'.*** Popular participation is high, for as watchers gather, the monster runs through the crowd looking for unvaccinated children. At the end of the skit, when all the children are protected by ***vaccination***, the children in the audience join the children in the skit in beating up the monster.



An unvaccinated child actor (wearing a white 'happy' mask) is caught by the measles monster, who closes his huge claws around him.



Under the monster's claws the child rapidly changes masks. When the monster uncovers him, he is wearing a 'sad' mask speckled with red spots. The child nearly dies.

The announcer of the skit asks the children in the audience why the boy was attacked. They shout back, "Because he wasn't vaccinated." At the end, after all the children are vaccinated, the loudspeaker asks, "Why can the children now overcome the monster?" They shout back, "Because we have all been vaccinated!"

To give another idea of what can be done through popular theatre, we will show you photos from 2 theater skits organized by Project PROJIMO, the villager–run rehabilitation program based in Ajoya, Mexico.

In order to increase community involvement in PROJIMO and to help local people understand its activities better, the program uses popular theatre. The skits were put on soon after the school children had helped build the rehabilitation playground. They tell the story of how PROJIMO began and how the playground was built and is used . The actors are local school children, disabled workers of PROJIMO, and village health workers from neighboring villages who were in town for a refresher course. The health workers participation in the skits gave them experience working with disabled persons and also gave them ideas for simple rehabilitation activities and aids in their own villages.





– the story of how Project PROJIMO got started and how village school children built a playground for disabled and non-disabled children.



A disabled young man (played by Marcelo, see p. 86) arrives at Ajoya and asks directions to the village health center (Project Piaxtla).

The health workers examine him, find he is disabled by polio and think he may need braces. But they lack the knowledge about what to do for him. So they send him away without helping him.



The health workers are concerned: "So many disabled children come to us. Most of them don't need hospitalization or surgery, but simpler things like braces or special exercises. Yet we don't have the knowledge or skills to provide these things for them. Why don't we try to get more training and start a rehabilitation program for disabled children here in our village? We can focus on what parents can do for their children in the home."

The health workers meet with villagers to discuss the new program. The villagers respond enthusiastically. Men offer to help fix up the center. Women offer to provide room and food for visiting children and their families. And the schoolchildren offer to help build a rehabilitation playground – on condition that they can play there too.

The schoolchildren – who had already built the actual playground for all children in the village–quickly rebuild the playground on stage.

Because they had already dug the holes for the poles, and had practiced over and over again, they were able to set up the playground on stage in about 3 minutes.

In this way villagers have a chance to see how different equipment in the playground is used – like this 'rocker board' to help children with balance problems, and the sitting frame to help a child with spasticity keep his legs apart while he plays with homemade educational toys.

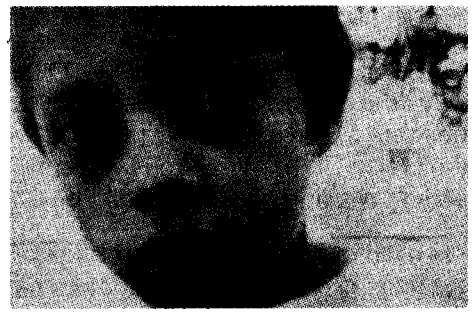




"Disability is not a hindrance–An awareness procession organized by Jan Madhyam.

The second skit is a continuation of the first.





This is the disabled child, Tristin.



His role is played by Ines – one of the disabled village workers. In fact, the skit comes close to telling Ines own story. Like Tristin in the skit, Ines is an orphan disabled by polio who was helped by PROJIMO to get braces, and then stayed on as a rehabilitation worker.

Marcelo, a village rehabilitation worker, finds Tristin in a village hut. The boy is unhappy because he cannot walk and has no friends. Marcelo invites Tristin to come with him to PROJIMO.



They arrive at PROJIMO and Marcelo shows Tristin the playground.

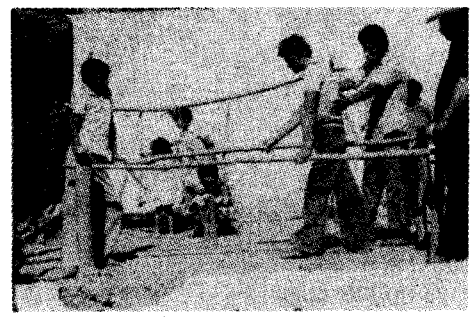
Tristin (and the audience) have a chance to see how the playground equipment is used to help disabled children learn to walk and do other things.



They see how the sitting frame and homemade games are used; also how a child who cannot sit lies on a sloping platform so he can lift his head and use his hands.

5 days later,

The village rehabilitation workers have made a brace for Tristin, and here fit it onto his leg.



Then they help him learn to walk with the brace, using the parallel bars.

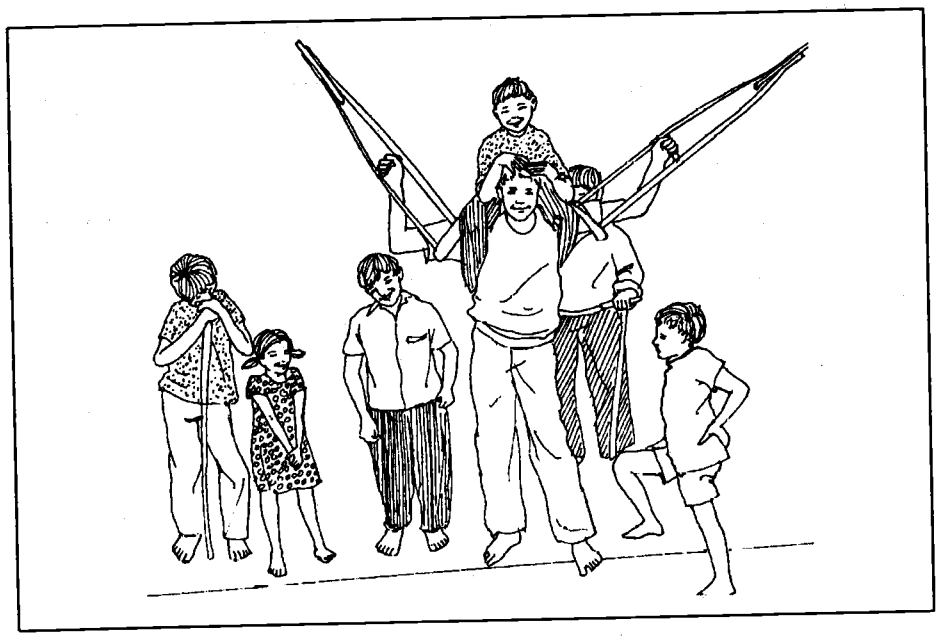
Tristin learns quickly and soon begins to walk with crutches.

The time comes when PROJIMO has done as much as it can for Tristin in terms of ***physical*** rehabilitation. "Where do you go from here?" they ask him, "I don't know," he answers, "I have no family to go to, I've never gone to school. Work is hard to get even for the physically fit, "Why don't you stay with us and help in the rehab program? You can learn some skills and help other children like yourself."

Tristin decides to stay, and begins to learn rehabilitation skills. Here a mother arrives with the first child for whom Tristin becomes responsible as a 'rehabilitation helper'.

Together the team examines the child, who appears to have cerebral palsy affecting mainly his legs. The team believes he has a good chance of learning to walk.

Tristin shows the child's mother how she can help him learn to walk using the parallel bars.



At last the little boy learns to walk. But just as important, he has new hope, new friends and new self-confidence. He sees other disabled persons like himself who are not only leading full lives, but who are working hard to serve others in need. As the skit ends, Tristin lifts his young friend onto his shoulders and raises his crutches in a sign of victory.

The ending of this skit was even more impressive for the village audience because they had seen Ines (who acted as Tristin) when he first came to their village. They knew that his transformation from a very disabled, withdrawn youth to a fast–moving, capable young man- was not just acted – it was real.

And because PROJIMO is the village's program, everyone felt proud.

Skits such as this organized by Jan Madhyam performed by mentally retarded children sensitize the audience to the abilities of such children and also give the children an opportunity for creative expression.

There is a "Jamun Tree" by the river. It is laden with black and juicy 'Jamuns'. There are birds, squirrels and monkeys on the tree. The children sing a song –

"What lovely Jamuns – black and juicy.

"I want to shake the branches and make the Jamun rain came. Let us gather them !

"But wait a minute, first to the river to wash and then to eat."

All the children are enjoying themselves under the tree.

Along comes a 'Toughie' to spoil the fun.

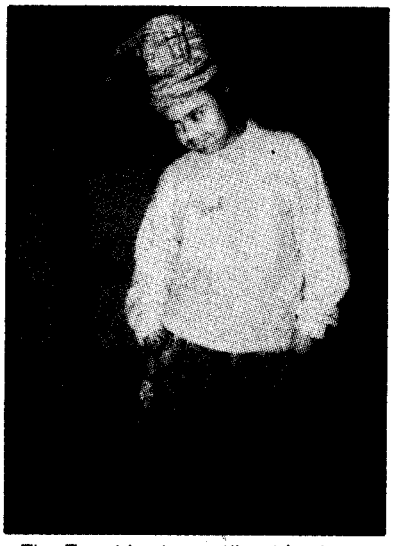
"Hey ! Where is my share ? I want some now, give me the Jamuns.

Oh... no ! scream the children, "We worked hard to get them – we climbed the tree. We shook the branches and gathered the fruit. You work with us and you will get a share too."

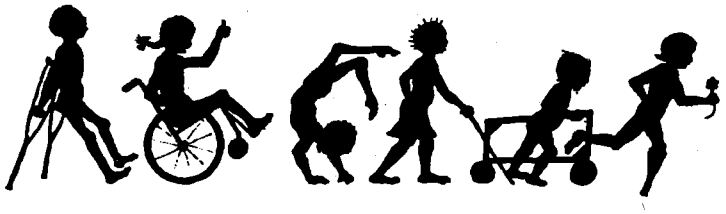
The Toughie decided that it was the only way he could get to eat the Jamuns.



Children getting ready to pluck Jamuns from the tree – A young girl dressed up as tree in a long gown and leaves, Jamuns and the birds made of coloured paper.



The Toughie demanding his share.



Sets of color slides (transparencies) with written scripts of the skits, "The Measles Monster," "Helping Your Neighbor", and "A Disabled Child Discovers New Life," are available from the Hesperian Foundation. Also available, although less directly related to disability prevention, are slide sets, "The Importance of Breast Feeding,", "Useless Medicines That Sometimes Kill", "The Women Unite To Overcome Drunkenness", and "Farmworkers Unite To Overcome Exploitation". Contact Jan Madhyam for more ideas on using traditional media and for training programs.

Other skits are mentioned in this book on p. 537 and 539.



Drawing by Minji Ng 6 years old, of herself with her artificial arm, and her friend Lupito, who is missing one leg and walks with a walker.



CHILD-to-child – A mentally retarded girl (right) teaching a normal younger girl to make papier mache. (Photo : Jan Madhyam)

CHAPTER **50**

A Children's Workshop for Making Toys

If a ***rehabilitation*** program is to achieve a strong base in the community, it needs to involve large number of local children. There are many important ways in which village children of various ages can take part, playing and working together with disabled children. We have already discussed how children can help build a low-cost 'playground-for-all children.'

Another way that village children can contribute to a rehabilitation program is by helping to make special toys for disabled babies and children.



Children often design and make excellent toys. This child from Vietnam puts the last touches on his homemade truck. (Photo: UNICEF/ Jacques Danois)

In Project PROJIMO in Mexico, village children help out in this way – and enjoy doing it. In addition to the toys that this voluntary 'labor' produces, it also brings together non-disabled and ***disabled*** children in a creative work-play relationship.

In this workshop, children are invited to make educational and useful toys – 'useful' in the sense that they help with a child's early development, providing ***stimulation***, exercise, use of the senses, and learning of skills.

Another advantage to the children's workshop is that it **provides experience, fun, productive activity, and skills training for visiting disabled children.** Thus a child who needs to spend a few days in the village, while a brace or limb is being fitted or a joint is being straightened, can spend part of his free time in the workshop.

Play is the first important step in a child's education, character development and social adjustment. It is through play that a child learns to discover and interact with other children. It is also a way of developing the inner resources of each child so that she can learn to play by herself.

It is important therefore to use play to its utmost, so that learning becomes an enjoyable process.

A children's workshop can easily make toys from low-cost or no cost materials by exploring the environment. The workshop can also widen its purpose and act as a toy bank or toy library by adding to its collections, toys purchased locally at low cost from the local fair or 'mela', the balloon seller, the local craftsman or artisan, or toys available during religious festivals. Children could also learn a lot about making toys under the guidance of a local potter.

India has a rich and colourful tradition of folk toys which are indegeniously crafted from locally available material. These toys often incorporate basic principles of science.

The third option is to purchase a few toys from the commercial market which now offers a very wide choice in toys.



Disabled children together with school children, at work in the toymaking shop at PROJIMO.

As the children or disabled workers become more skillful at making toys, some can be sold to bring in money to the workers or program. Some of these toys and dolls made at PROJIMO are sold to visitors. In Jamaica, disabled young people run an economically successful factory making wooden toys. Toys made at the **Life Help Centre for the Handicapped** at Madras, are sold **world – wide.**

Gathering materials and supplies

Explore every opportunity to obtain low- or no-cost materials and supplies for making toys. Here are a few possibilities:

- Many materials for making toys can be gathered from local forests – branches of trees, reeds, bamboo, wild kapok (cotton). Also various nuts, seedpods, and seashells can be used.
- Broken fruit-packing boxes often have thin wood that is excellent for toy-making. Even the nails can be pulled out, straightened and reused.
- Old tubes of car and bike tyres provide elastic bands for many toys.
- Scraps of wood, wire, and other supplies left over by lumber stores, builders, etc. will often be donated if you explain why you want them.
- Clothing makers and factories may have scraps of cloth left over.
- Cardboard cartons, especially thick ones (even if broken) provide material for making toys : Ask in local shops. Also ask in saree shops. They have many cardboard cartons for keeping their expensive sarees.
- Old cans, tins, plastic bottles, thread spools and so on are also useful. Ask members of the community to look for and collect these and other supplies.

When you start a toy making or collecting workshop, remember

- Something of value can be learnt from every toy. Seek it, and use it to the utmost.
- Disabled and non-disabled children can largely play with the same toy. But age levels and comprehension may vary. Sometimes, a very simple adaptation to the same toy can make it easier for the disabled child to play with it. For example, it is easier for a visually disabled child to play with brightly coloured toys.
- Children, especially disabled children, learn and play best when they can interact with the toy using all their sense and thereby learning from it in a variety of ways.
- Try and use the same toy for a variety of different purposes.
- The safety of toys is most important. See that there are no sharp edges or splinters, screws and nails that are loose. See also that there are no loose parts which can come off and be swallowed or put into the eyes , ears or nose.
- In a community rehabilitation program it is essential for children to have lots of toys- different playthings for children at different levels of development with different strengths, weaknesses and interests.

There is an old saying

"THEY WHO CHOP THEIR OWN FIREWOOD WARM THEMSELVES TWICE!"



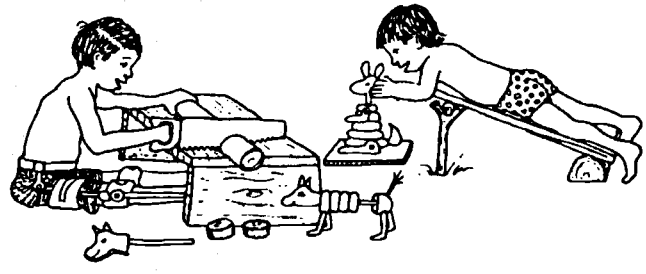
We have a new saying

"THE FAMILY THAT MAKES ITS OWN TOYS HAS TWICE AS MUCH FUN!"



Stuffing a homemade doll with cotton or rags

Many of the most fun, most educational toys can be made from scrap materials by members of the family or community. Disabled children with good hands can learn skills and take pride in making toys for other disabled children.



Helping to make toys for other children can be just as educational – and fun – as playing with them.

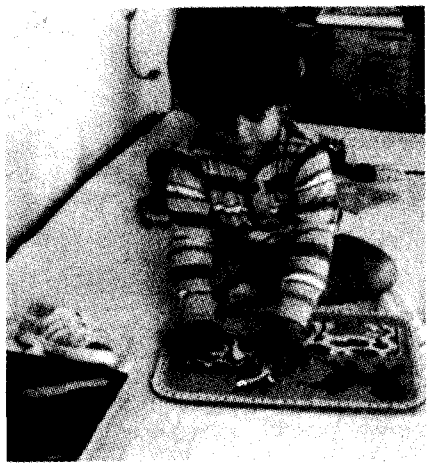
TOYS CHILDREN CAN MAKE AND COLLECT

The following pages show a number of toys that children will enjoy making and collecting either at home or at a children's workshop. We start with very simple toys for babies or children at an early developmental level. Gradually the toys become more advanced. More skills will be needed by the children who make them and by those who play with them.

The Indian toys in this section have been taken from 2 sources. The examples of folk toys are from a book entitled 'Dynamic Folk Toys' by Sudarshan Khanna.

The other examples are from 'Ujjwal, a voluntary organization which seeks to promote the development of human resources within a community by focussing on the needs of young children. One of its major activities is to provide stimulating, open ended teaching material and toys for the early development of both disabled and non-disabled children.

IMPORTANT: Please don't just copy the ideas toys shown here. Be creative and **encourage the children making the toys to be creative.** Help them use the examples shown on these pages as triggers to the imagination. Have fun !



Animal puzzles, like this one made by village children, help a child learn to use his hands, and to match shapes. (PROJIMO)

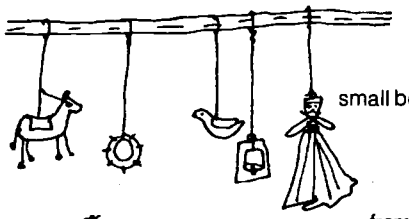


Making toys for themselves and for other children.

TOYS TO ENCOURAGE LOOKING AND LISTENING

small mirrors or pieces of tin foil or shiny paper

colourful objects that move in the air

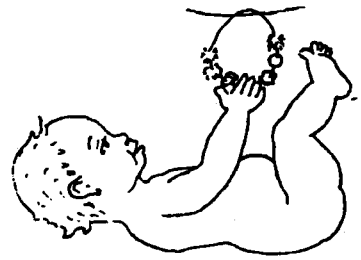


small bells



from UPKARAN manual (See p. 642.)

For a baby, hang a 'ring of beads' where she can reach and handle it.



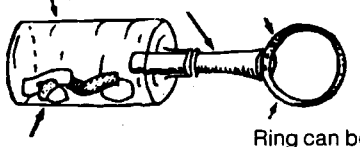
RATTLES AND OTHER NOISE TOYS

Plastic bottle rattle

a see-through plastic bottle

stick of wood

ring cut from a plastic bottle, bamboo, or whatever

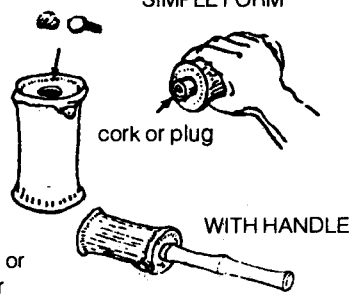


strips cut from plastic bottles of different colors, colorful stones, nuts, etc.

Ring can be wrapped with strips of cloth or tyre tubing for easier grip.

Bamboo rattle

SIMPLE FORM



cork or plug

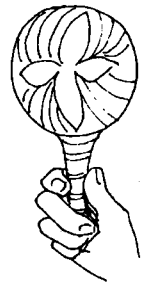
WITH HANDLE

If the child drops or throws his toys, try attaching strings and help him learn to get them back by himself.



Traditionally, rattle toys are made differently in different regions of the country. A variety of materials such as waste paper, clay, palm leaf, seeds and papier machie are used.

This 'jhunjhuna' (rattle) is traditionally made in Jodhpur, Rajasthan. It is made with papier machie with pebbles inside. It is first moulded in two halves which are then stuck together. (From Dynamic Folk Toys).





This 'ghughro' (rattle) is made in Ahmedabad. The materials used are paper, bamboo, grain particles and string. (From Dynamic Folk Toys).

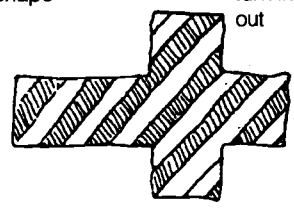
Soft rattle

use a small can or bottle with a small stone inside

or use 2 small bells

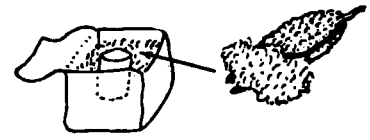


cut a colorful soft cloth this shape



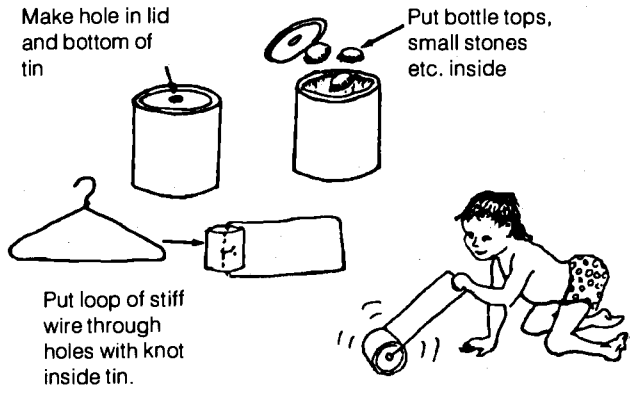
sew it into a square and turn inside out

Place can or bells in cloth square and pack cotton or bits of sponge around it. Sew it shut.

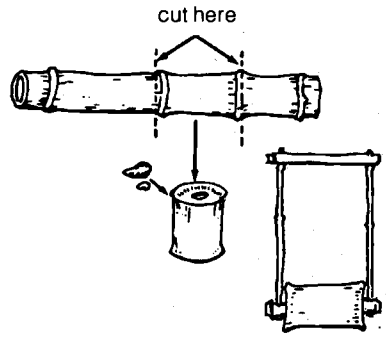


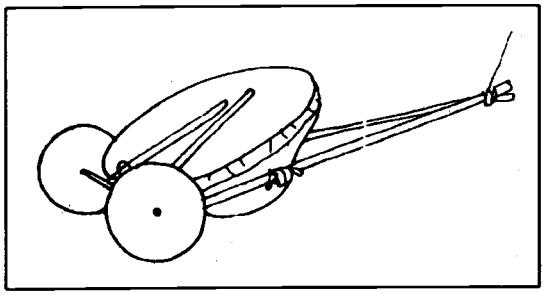
wild kapok (cotton)

Push-A-Long Noise Toys



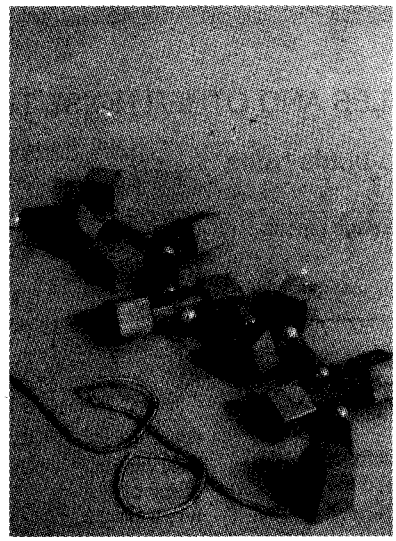
Bamboo push-a-long





Gari Bajna

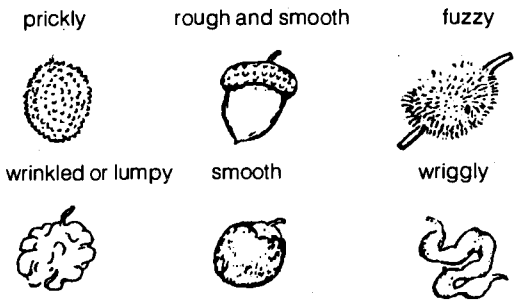
This drum-cart makes loud rhythmic sounds when pulled along by a string. It is tapped by two spring loaded sticks. The tapping is guided by the 'ratchet and hammer' device of the toy. The drum is made of a fired clay container which is covered by thin bamboo paper. It is made and easily available in Calcutta. (From Dynamic Folk Toys).

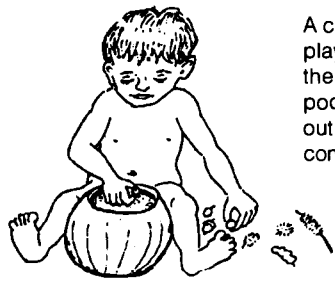


snake-a pull-a-long toy that moves on cubes (Photo: Ujjwal)

TOYS THAT HELP DEVELOP USE OF HANDS AND SENSE OF TOUCH

You can make beads and chains out of wild fruits and nuts.





A child can play putting the nuts and pods in and out of a container.

Later he can learn to sort them-first by seeing them, and them, and then blindfolded

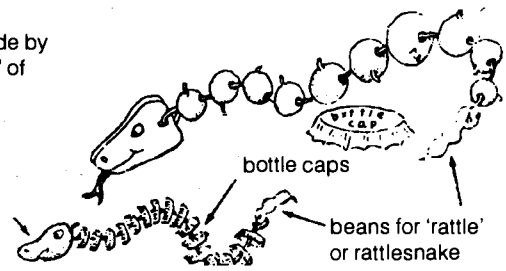


As the child develops more hand control, she can begin to make chains and necklaces by stringing the nuts on a cord.

CAUTION : Be sure not to use things that are poisonous, harmful, or that might get stuck in the child's throat, nose, or ears.

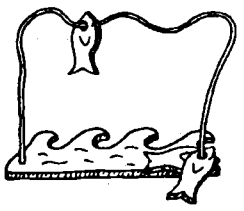
'Snakes' can be made by stringing nuts, 'caps' of acorns, bottle caps- or any combination of things.

small green mango (or whatever you can think of)

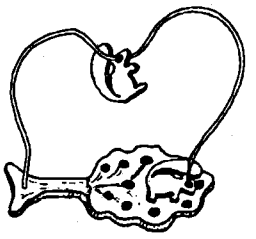


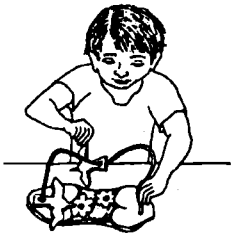
Slide-on wire toys

To help develop fine control of hand movement, blocks, beads or animals can be moved along a wire. Children with poor control need only move the figure from one side to the other. Children with good control try to move the figures without touching the wire.

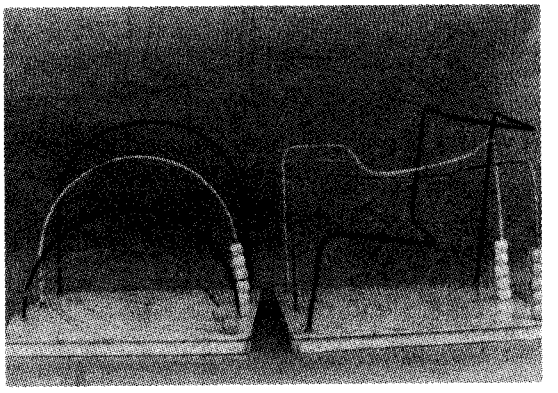


To make it more interesting, match the animals with wooden bases in the form and colors of the place the animal lives: fish in water, squirrels in trees, birds in flowers.



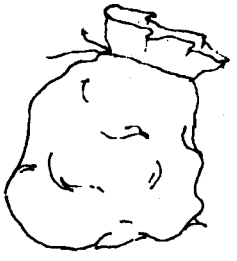


The more bends you put in the wire, the harder it is.

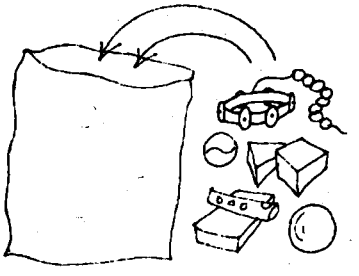


(photo : Ujjwal)

Touch



You can always make your own feely bag.



Take a cloth bag and fill it with objects the child is familiar with.



Then get the child to touch and feel each object and recognize it.

Although this is a toy used by all children, it is particularly helpful for a visually impaired child to develop a sense of touch.

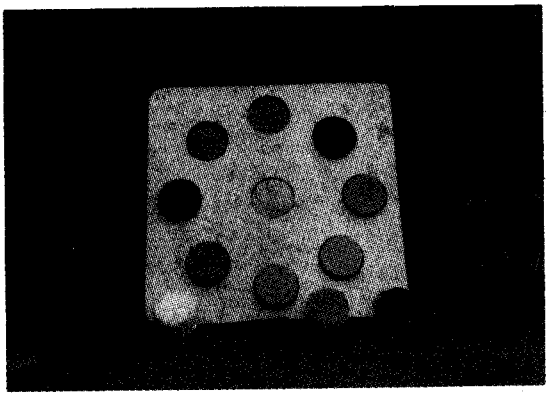
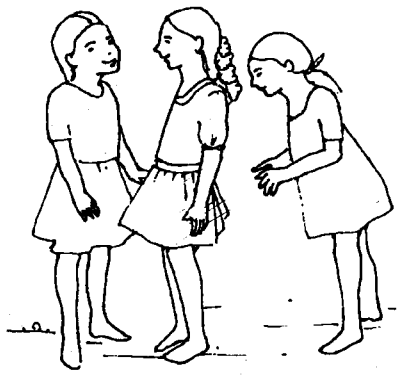


Photo: Ujjwal, Touch trainer

There are nine different textures in the tray and nine discs with matching textures. Children are to feel the textures on the tray and find the matching disc by touch only. Play blind folded if you like.

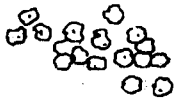
SMELL AND SOUND

Explore different ways of developing all the 5 senses of the child. You can use the environment for developing a sense of smell and for making out the difference between different smells.

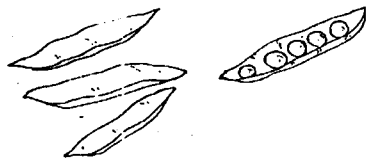


For this use flowers, fruits, spices, vegetables etc. Get children to identify smells they like and those which they dislike.

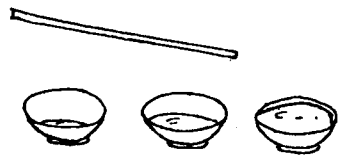
A variety of materials can be used to identify sounds.



Dry beans

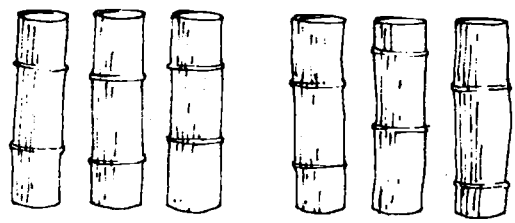


Pods from the Amaltas (Laburnum) tree



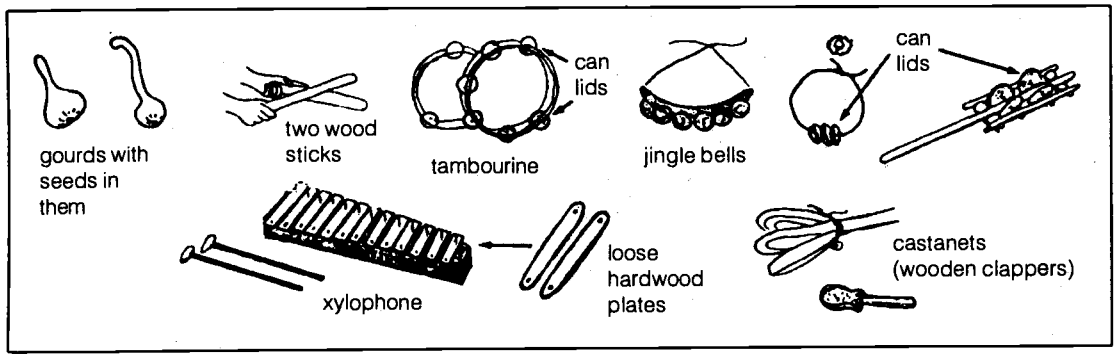
Fill these cups with water at different levels and create a musical instrument with different sounds.

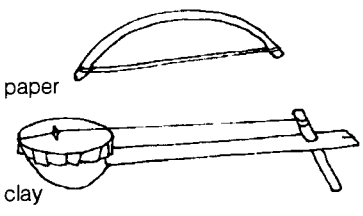
You can make a series of 'sound boxes' by using hollow bamboo sticks. Seal the bottom end with a piece of wood. Fill each bamboo section with different materials such as stones, seeds, dals. Now seal the top with a piece of plywood or wood. Paint the top of one set *red*. Paint the top of the other set *blue*. Children can play a game of matching the red sound boxes with the blue.



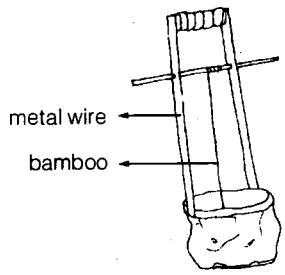
Red Blue

IDEAS FOR HOMEMADE MUSIC (From *How to Raise a Blind Child*, see p. 771 and Dynamic Folk Toys).





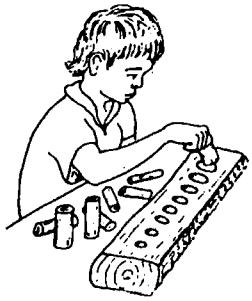
Sarangi (a musical instrument made in Ahmedabad). Makes sounds similar to the classical sarangi. Easily available in nearly all parts of the country. (From Dynamic Folk Toys).



Ektara (a string instrument made in Cuttack, Orissa) Makes a melodious sound produced by string vibration. (From Dynamic Folk Toys)

COLOR AND SHAPES

Games fitting pegs or blocks into holes help develop better hand control and 'hand-eye coordination'. They also help the child learn to compare sizes, shapes, and colors. The pegs or shapes can be painted or coloured so that the same toy can be used for color, counting, shape, fitting etc.,

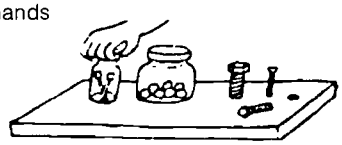




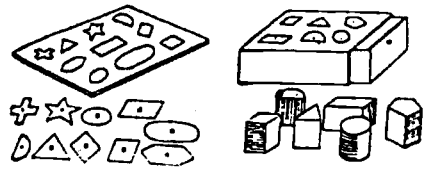
Drill holes in a piece of wood and cut pegs from tree branches.

Or you can cut holes in a cardboard box. Glue an extra layer of tough cardboard on the top.

Also, make games that help the child develop a twisting motion in her hands and wrists.



Other ideas

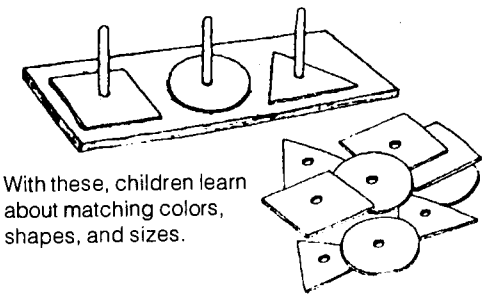


(These could be made of wood or even cardboard.)

SORTING AND MATCHING

These activities help in developing a logical thought process. The child's mind gets more ordered by observing similar and dissimilar features. She is then ready to master more complex abilities. Sorting and matching games range from the simple to the more complicated.

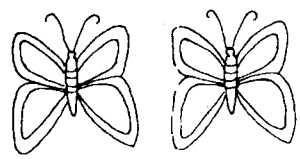
Shapes on pegs*



With these, children learn about matching colors, shapes, and sizes.

You can use things in your environment like flowers, leaves, seeds etc to play matching games.

You can draw figures on cardboard and chart paper, cut them out and use them to play matching games. You can make exciting colorful matching cards with pictures cut from old magazines, newspapers or even cards. Teach children to match colors, flowers, birds and other common objects in their environment. Increase the complexity of matching by asking children to match for example red flower with red cloth or dress. Later get children to match animal with their food etc.

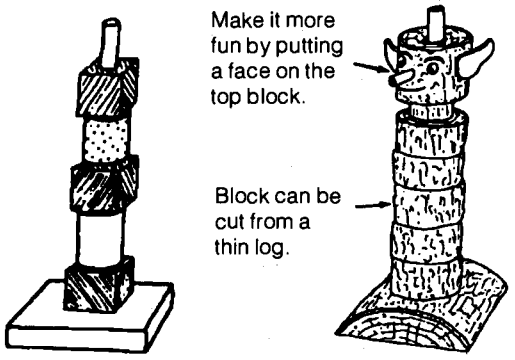




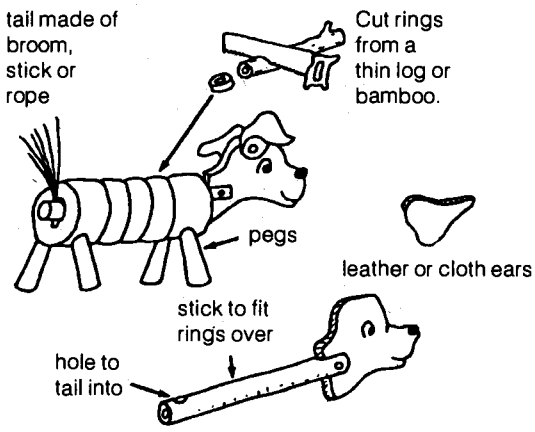
At a later stage you can add numbers to your matching game. Two yellow flowers matched with two yellow butterflies.

BLOCKS: Every child needs to create to coordinate between his mind and hand. Blocks are the ideal materials for learning scenes and for children to build their own magic world. Encourage them to play often with as many blocks as possible.

Blocks for building a tower on pegs



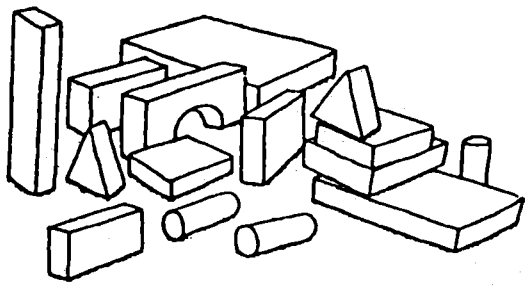
'Animal stackers'



These are from the UPKARAN Manual (See p. 774.)

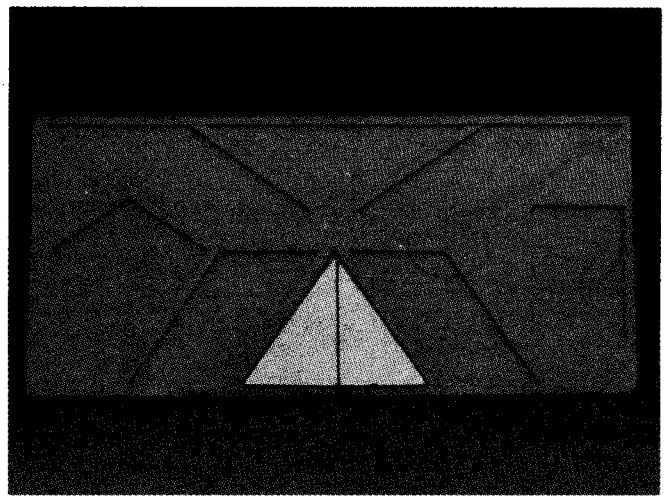
Building blocks*

(of wood, clay, or layers of cardboard)



Tiles for pattern formation help the child to use her imagination and creativity. Pattern formation is an ideal base for developing mathematical abilities while being creative and having fun. Use as much symmetrical material as you can obtain from your environment for this.

You can also cut out colorful pieces of cardboard in geometric forms and allow children to explore the possibilities of play with this. This is good for children who are slow learners, or those with hearing and mental disabilities.



A variety of shapes are cut out on the tray but there are only two triangles. The children try to get both these triangles into all the shapes in the tray. Photo-Ujjwal

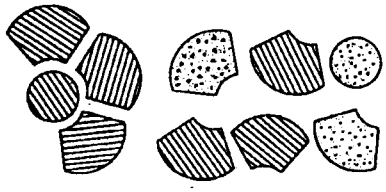
PUZZLES

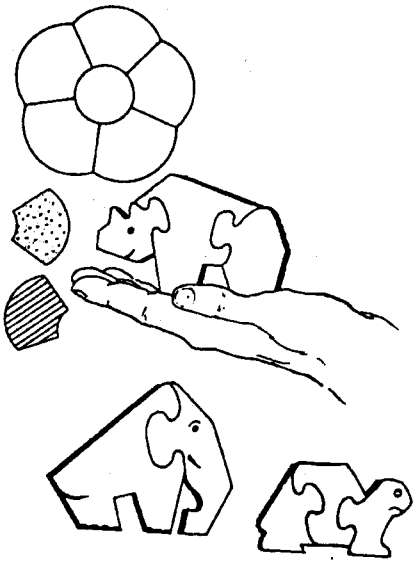
Puzzles can help a child learn how shapes, forms and colors fit together. Puzzles can be made by glueing a picture on **cardboard, wood, plywood** or other materials. Puzzles can also be made in various styles. We give a few examples.

Flower puzzles

Children can first learn to form one flower.

Later, they can play 'sorting games' with flowers of different colors.



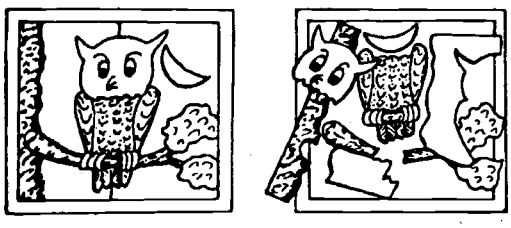


Several children can play to see who can complete a flower first- using dice with different colored sides.



Puzzles with cut-out pieces that follow the forms and lines of the drawing.

First have the child build the main object (here, the owl) with a few pieces. Later, she can learn to fill in the background.



An outer frame helps hold the pieces together.

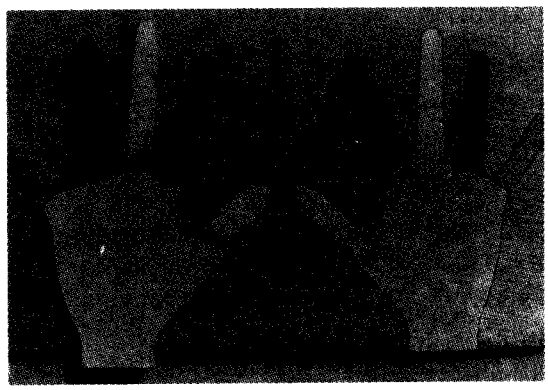
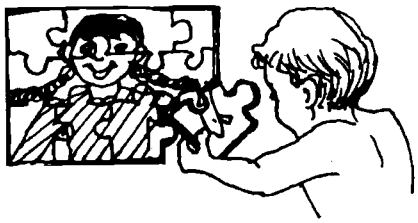


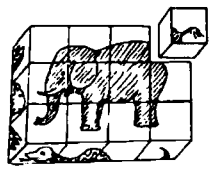
Photo: Ujjwal

Puzzles with interlocking pieces



Suggestion: If you have a large photo of the child or a family member, glue it on cardboard and cut out the puzzle. Or use a picture from a magazine or calendar.

Block puzzles

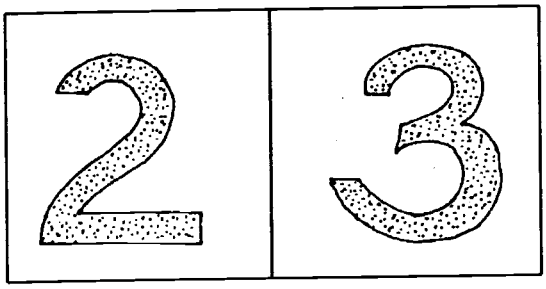


Glue 6 different pictures to the sides of a thick board or sheet of foam plastic, and cut it into blocks. You can also make blocks from cubes of clay or small match boxes.

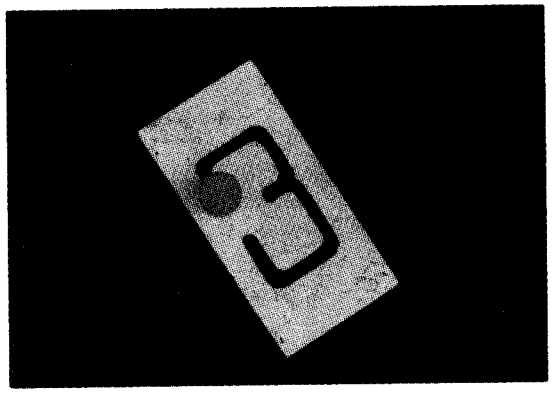
Ideas for the toys shown in this chapter are from many sources, including books. For books on toys and games, see p. 773. Other toys are on pages 302, 387, 388, 417, 425,and 480.

Learning numbers

Understanding and learning numbers is essential for every child. Yet, numbers are abstract symbols and are difficult to understand if the child does not have material to play with to assist her understanding. Almost anything and everything in the environment can be used for helping the child understand numbers. Here are 2 aids designed and produced by Ujjwal to specially help disabled children understand numbers.



Sandpaper numbers.
The numbers are cut out of sandpaper and pasted on cardboard or wood or any other material. A visually disabled child will find it easy to trace the numbers with his hands and learn their shape.



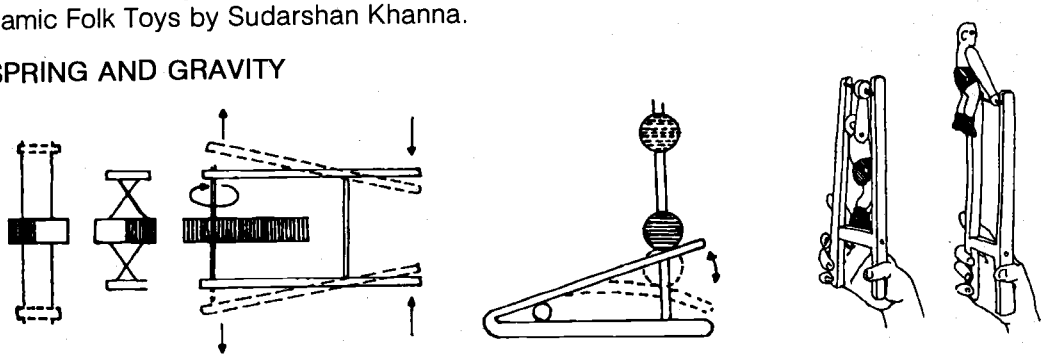
Motor numbers.
The child can trace the shape of the numbers with the knob. This toy is particularly useful to children who may have a problem using their hands. Photo : Ujjwal

TOYS THAT ARE FUN AND ALSO BASED ON PRINCIPLES OF SCIENCE

- You can collect them. They are easily available.
- You can try and make them.
- Through them, you can learn about many wonderful principles of science.

The important thing about these toys is that they appeal to the child's senses; they create movement; change form and make sounds. Here we show you a selection of such toys which are folk toys and easily available. The examples are all taken from the book 'Dynamic Folk Toys by Sudarshan Khanna.

SPRING AND GRAVITY

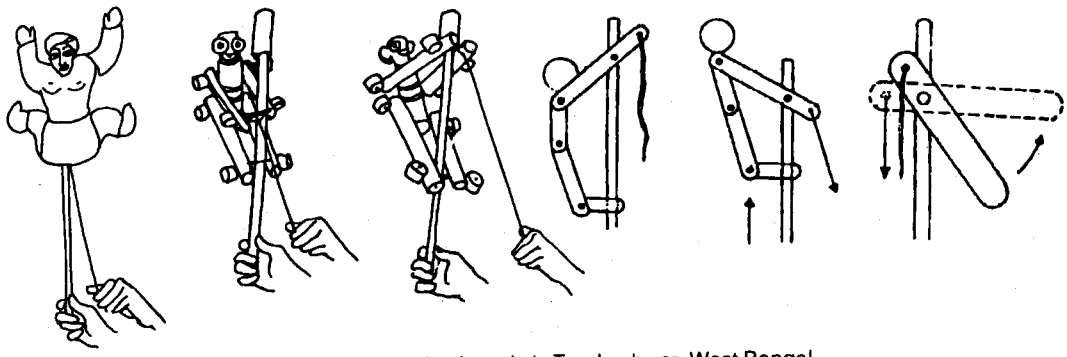


Nat (Acrobat) made in Ahmedabad.

To make this toy, all you require is some pieces of cardboard, wooden pieces, nylon string and a few nails. The acrobat jumps up and then down as the child puts and release pressure on the two vertical wooden pieces. This toy is based on the principle of spring and gravity.

String manipulated toys

The movement in these toys is generated by applying the principle of the lever. The string is attached to different parts of the toy When it is pulled, the parts move against gravity and on the release of tension, return to their original position.



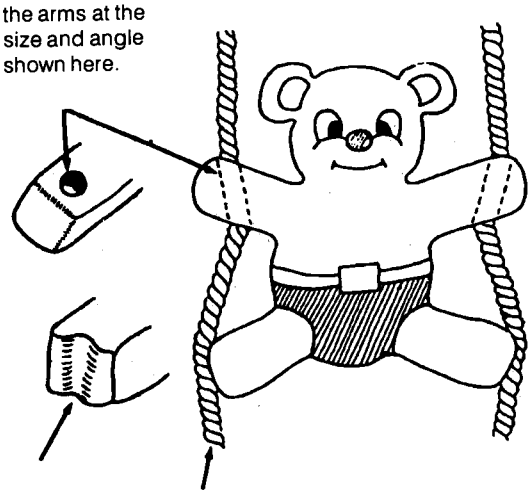
Bander (Monkey) made in Tarakeshwar, West Bengal.

Materials used-string, broom stick, cardboard or thick paper is the material most often used for making these puppets. Pith or 'shola' a plant that grows wild in the eastern region of India is also used.

Climbing bear

Cut a pattern of the bear out of a wood board about 2cm. (3/4 inch) thick.

Drill holes through the arms at the size and angle shown here.



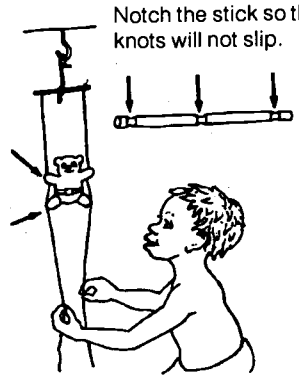
Hang a stick from the roof or a tree limb.

Tie cords or leather thongs tightly to the ends of the stick and pass them through the arm holes of the bear.

Be sure the cord passes through the notches in the feet.

Notch the ends of the feet so the cord can slide through the notch.

Notch the stick so that knots will not slip.

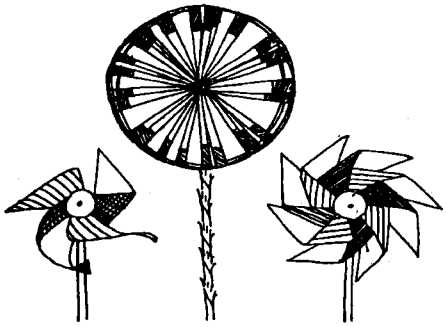


By pulling one cord and then the other, the bear will climb the ropes! Children love it!

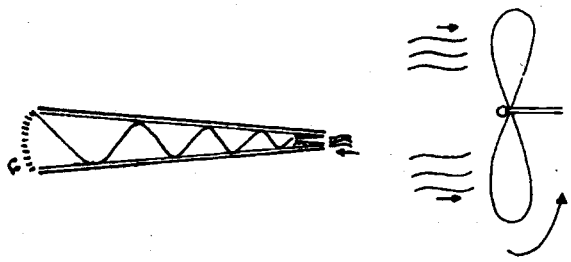
Good for developing use of both hands together.

Wind, wheel and whistle toys

These toys are based on the principle of wind energy. They use the force of blown air which is converted into movement, sound, or both.

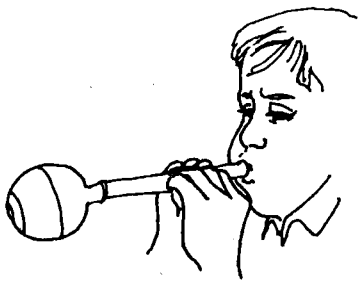


Chakardi (Wind wheels) made throughout the country.



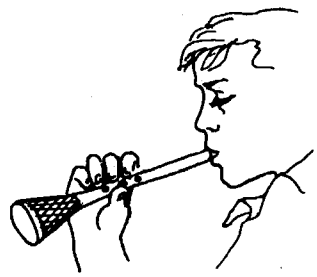
The principle from Dynamic Folk Toys.

The wind wheels rotate on the axis when placed in the direction of wind flow. These toys are good for children who have speech problems and who need to practice 'blowing'.



balloon bansi

All you need is a rubber balloon, a bamboo flute and a piece of thread. When air is blown, it inflates the balloon and then makes a melodious sound. (From Dynamic Folk Toys)

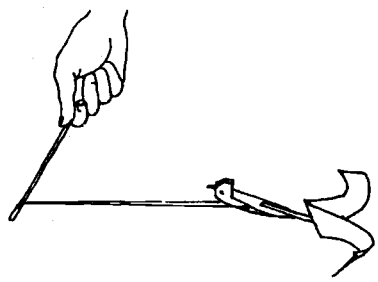


Flute

Paper, Palm leaf, bamboo and clay are the materials generally used to make these toys. They can be made by semiskilled persons with the use of simple hand tools.

Friction toys

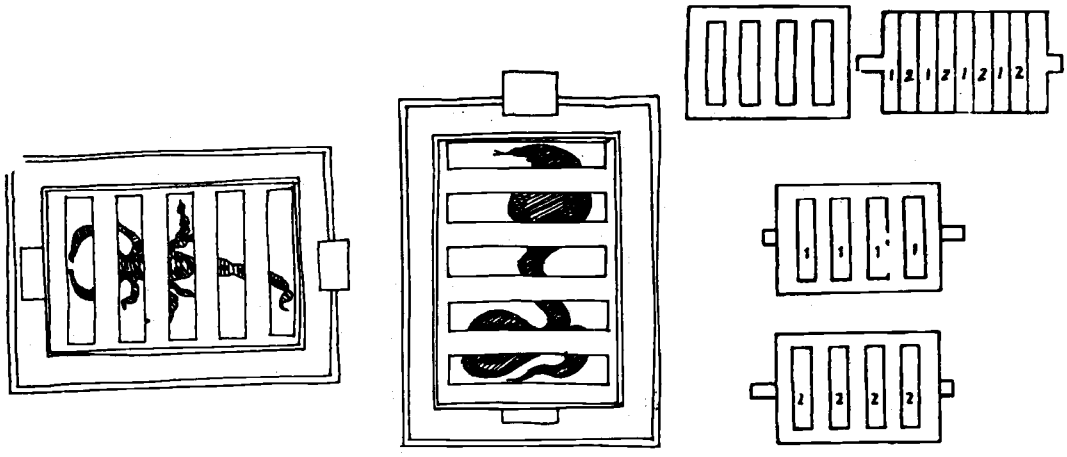
Based on the principle of sound through friction.



When the sparrow toy is swung in the air its, paper blades rotate showing a sparrow in flight. At the same time the pointed metallic strip scratches the rotating metal disc which produces a sound resembling sparrow calls. (Dynamic Folk Toys).

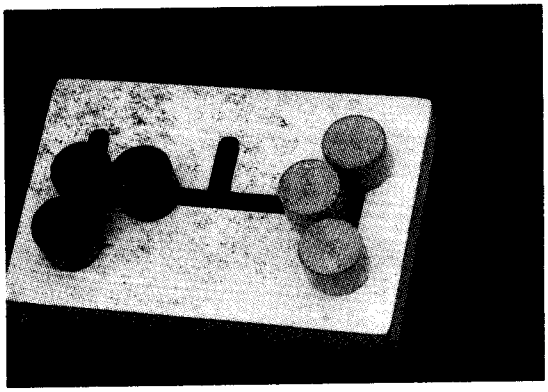
Mystery toys

Children can even learn to make their own magic and mystery toys. All you need is some paper, cardboard and the ability to draw. These toys are based on the principle of construction tricks.



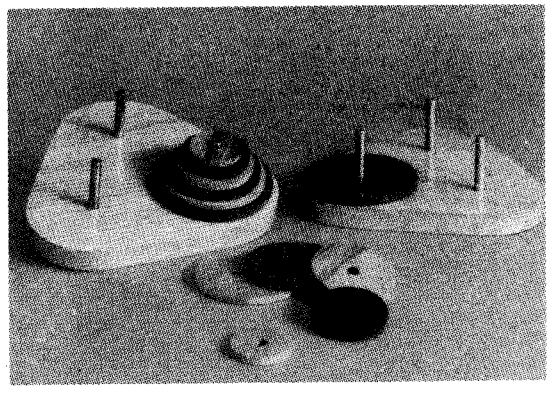
PROBLEM SOLVING GAMES

These toys are designed so that children can play with them by themselves and develop problem solving abilities through play. Most of them are based on sound principles of mathematics. They are particularly useful for children with hearing, motor and visual disabilities since they occupy the child in constructive activity without outside participation.



Parking puzzle

The child is required to interchange the positions of the knobs, using 'P' as the parking place. See if the child can do it in 16 moves. (This game has been very successfully used by the integrated education program in India.)



Bhrama's tower

Here the child is required to transfer the pyramid formation from any one peg to another. The rules are- remove only one disc at a time and do not place a large one on a smaller one.

This game can be easily made by using a cardboard base and glueing three bamboo sticks or sharp pins on to it. Cut out five discs of increasing sizes. Paint alternate discs in red. Leave the others unpainted.

NOTES

Organization, Management, and Financing of a Village Rehabilitation Program

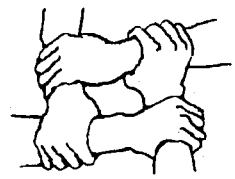
CHAPTER 51

ORGANIZATION AND MANAGEMENT – A 'PEOPLE-CENTERED' APPROACH

In Chapter 46 we spoke to top-down and down and bottom-up approaches to a community program. Programs that are 'bottom-up' or begun by disabled persons, family members, and concerned members of the community, tend to be organized and managed very differently than top-down programs.

A sense of equality among all persons taking part in or benefiting from the program is basic to the organization of bottom-up or 'people-centered' programs:

- Everyone is considered equal.
- Leaders are coordinators, not bosses.
- Decisions are either made by the group or can be openly challenged by the group or by any of its members.
- Everyone has the same rights and deserves the same respect. The ideas and opinions of a disabled child or her parents are just as important as those of the village rehabilitation worker or visiting professional. All are equal and valuable members of the rehabilitation team.



In a people-centered program, goodwill, friendliness, and a feeling of shared pleasure in meeting each other's needs are often given more importance than polished floors, arriving on time, exact records, number of hours worked, or how many wheelchairs are produced by each worker each month. Success of the program is measured not so much by formal ***evaluation*** as by the 'smile factor': how good everyone-workers, parents, and children-feels about what they have put into and received from the interaction.



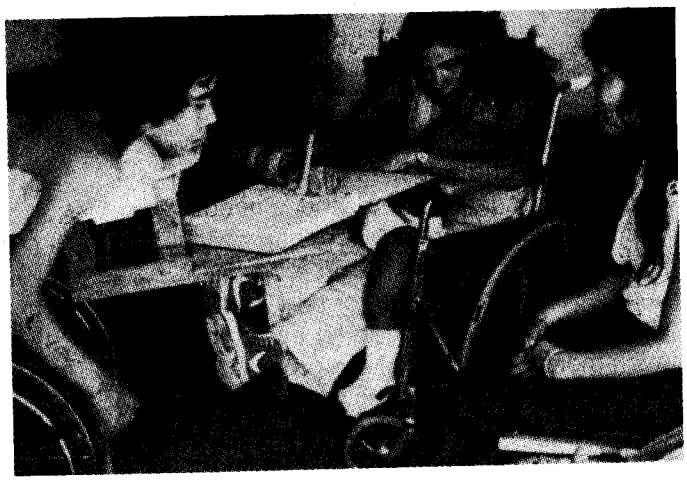
THE SMILE FACTOR–perhaps the best measurement of a program's success. (Photo: UNICEF/T. S. Satyan)

The PROJIMO approach: Informal organization and team management

We who work at, PROJIMO are in no position to speak with authority about 'organization and managements. Sometimes we wonder if our achievements are due more to our **disorganization**. Whatever organization and management we have is informal and more or less cooperative. Not only are there no clear-cut divisions between 'managers' and 'workers', but even the division between 'workers' and 'patients' is unclear. (In fact, we avoid words like 'patient' and 'client'.) Parents, children, visitors, and everyone else are invited and expected to help out in whatever way they can. Most members of the PROJIMO team are disabled young persons who first came for rehabilitation or aids. They began to help out as best they could, and finally decided to stay to learn and work. Some stay a few weeks or months, learn new skills, gain confidence, and then go on to something else. Others stay for years. Some come and go, and return again.

PROJIMO is like a big family, mainly of young people, growing up together. Most of the work team is made up of young persons who are themselves benefiting from rehabilitation, learning to work, and learning to relate to each other. It would be a mistake to use the same goals and measure of production efficiency as you would for a shop that employs already trained and experienced workers. There is no boss to give orders. Yet the needs of the disabled children place a demand on the group to work relatively hard, and to accomplish what they can. Hours are flexible. There are quiet afternoons where half the workers suddenly decide to go swimming in the river. And there are busy days when several team members work until midnight to finish a brace or limb or wheelchair for a family that needs to return home on the mornings bus. They choose to work overtime, not because someone tells them to, or because they get extra pay, but because a child's father explains that he cannot afford to miss another day's work or a mother is worried about a sick child she left at home.

When a situation arises that will require extra work and responsibility, the group as a whole decides if they think they can handle it. For example, one time a teen-age boy named Julio arrived who was almost completely ***paralyzed*** (quardriplegic). He had severe pressure sores, and was totally dependent for all his daily needs. The team, which had no one specially trained in nursing care, met and discussed whether they could accept Julio in PROJIMO, since no family member was prepared to stay with him. Some argued against accepting him. Others argued in favour, pointing out that his home situation was miserable. (His stepfather resented his mother spending time with the boy.) At last the majority decided to accept Julio, even though a few team members said that they would not be willing to help in his care. It turned out, however, that some of those who had at first been unwilling became those who spent the most time with Julio. Not only did the group do an excellent job in healing his pressure sores and tending his personal needs, they became his close friends.



Today Julio is one of the leaders of PROJIMO. Every evening he records the work done by each member of the team.

The team invited Julio to take part in ***evaluating*** the needs of other disabled children, so that he could learn history-taking and advisory skills. They also gave him the job of chief ' work checker' His job was to keep a list of the various jobs that needed to be done each day and who was responsible for doing them. He would check to see that the jobs were getting done and speak to those who needed reminding. Since he could not get around easily, the group agreed that when Julio asked anyone to send someone to him, her or she would do so. Thus Julio, as the most severely disabled team member, was given the most power in terms of program management. This is in agreement with the politics of the program, that **only through a just redistribution of power will the weak and marginalised gain a fair place and voice in our society.**



The fact that PROJIMO has no 'boss' creates certain problems while it avoids others. Individual concern, group pressure, children's urgent needs, and parents' appreciation are the main motivations to do a good job. Some team members work much harder than others. When someone is not working enough or other problems arise (such as rudeness to families) the group meets with the person. In extreme cases the person may be asked to meet the group's expectations or to leave. So far, however, those who have left have done so by their own choice.

Different team members are able to work at different speeds and effectiveness, depending on their ***disabilities***. Therefore, the group judges a person's work not by how much he produces, but by whether or not he is doing the best he can. A person who works responsibly gets higher pay, even if unable to work fast. Within the limitations of money available, the group decides how much different team members will receive. New team members who are learning work habits and skills begin as volunteers, with only their room and food paid. Later, they earn more, depending on how responsibly and steadily they work. The group decides.

The team meets regularly to plan activities and to decide who will take responsibility for what jobs. Different persons take charge of different aspects of the program: consultations, record keeping, accounting and different shop activities, such as aids making or wheelchair making. Playground maintenance, housekeeping, cooking and clean-up is usually done by turns. One person keeps track of the hours worked each day by different participants and this is used as a guide for monthly wages.



Members of the PROJIMO team at a weekly meeting

This whole organizational approach is informal and loosely structured. It is a process of ongoing experimentation and change. In short, a group of people are learning how to work and live together as equals. Sometimes things seem to work out better than others. It is the adventure of it all that keeps everyone going – the challenge to create a friendlier and fairer social order, if at first within only a small group.

Planning and management of CBR in India

In the field of rehabilitation, the process of decentralization is inevitable. Even though a large number of services continue to be institution based – they have high costs, wastage of manpower and inefficient. The CBR approach on the other hand is viewed as a cost efficient and more decentralized approach. The philosophy of CBR is to integrate disabled people into the society rather than create special environments for them.

Experience in the field have also shown that the rehabilitation process can be simplified and that it can be carried out by people who are non professionals.

PLANNING

Here we give a brief and very general overview of some of the factors to consider, in the planning, management and financing of community based program in a country like India.

In the early stages of planning a rehabilitation program, we need to be clear about the different kinds of disabilities we are going to be working with. While a large number of community based rehabilitation programs have been working with people with a particular disability, there is now a growing trend towards providing services for all the disabled members living in a community.

A knowledge of the community and the resources it has is equally important, while starting a community based rehabilitation program. The attitudes of the community towards disabled people, it's caste class and religious structure, the existing family structures, their social and economic activities; the felt needs of the community; and finally, the impact of the disabled person on the life of the community— all these will affect the way we plan any rehabilitation program and its services.

Much will also depend on the levels of voluntary and group activities in the community, the extent of networking that is possible and the existing facilities and infrastructure for carrying out program activities. Factors such as the gradual abandonment of the joint family and the growing poverty of people in villages have lessened the resources available for the rehabilitation of disabled people. Populations of disabled people are limited, especially because more and more people in the villages are becoming poorer.

Integration of rehabilitation services

Rehabilitation services can be integrated into existing systems, since the cost of setting up an independent program is often very high and the number of disabled people to services to, very large. Infact, India's primary health care system is fairly well established, covering about 80% of the country's population that lives in the rural areas. Integrating rehabilitations programs with the PHC scheme or health care systems in general would be a cost effective way of reaching out to disabled people who live in remote rural areas. This would however, require good referral systems. People already working in related areas could also be trained as multipurpose workers, to work with disabled people.

Experience in the field have shown that a majority of only about 30% of them would

need to be considered while planning a community based rehabilitation program.

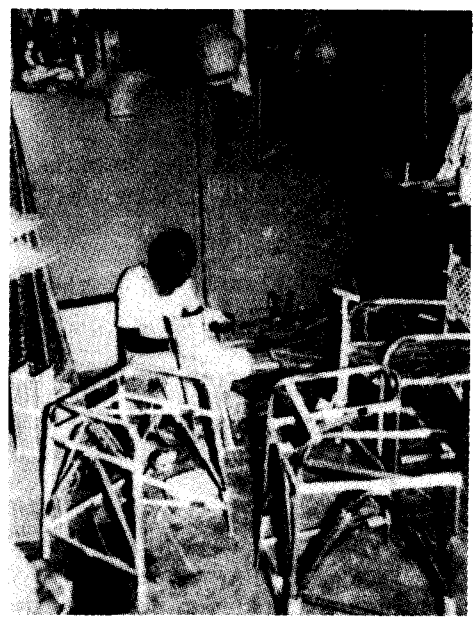
THERE **IS NO IDEAL VILLAGE** Rehabilitation programs are often designed to suit the ideal village with the assumption that development in a community is linear. In practice however, no village or community is ideal. The process of development is a dynamic one, differing from one village to another and in the same village from time to time.

For example, a state like Kerala differs greatly from Bihar in terms of factors like gross national product, literacy, health, education, voluntary service etc., The model for a community based program for Kerala will therefore differ from that of Bihar or of the hilly areas of the North Eastern region. The need for flexibility is therefore, evident and the factors that may be responsible for the success of a CBR program should be viewed in the context of the status of the development process in the community. A lot depends on "who will work in the program?" Much depends on who works in the program.

Professionals who do not live in the community often have short staying power and may not be able to come into the community on a regular basis. But professionals who come in to advice and guide motivated members of the community are an invaluable asset to families of disabled people are an important resource for any program. In Bangalore, groups of family members have joined to form self help groups at the community level. These groups are able to manage programs and work together on many aspects of the rehabilitation of their children. Families have found that the support offered by these groups was very useful to meet their day to day needs as well as to initiate other activities. However, the groups do require constant support from professionals and organizations working in the community.

Parents Association are now beginning to form in many parts of the country, often as an offshoot of an already existing program. Many of them are going on to register as societies or trusts and are initiating programs for their own and other disabled children.

Training motivated people within the community is another good resource for a community based rehabilitation program. Many organizations now run courses training multipurpose rehabilitation workers, from within the community. (see page. 495)



Organizations such as the Viklang Kendra at Allahabad have successfully motivated and trained village artisans to use their skills within the rehabilitation program (see pg. 654)

Evaluation of community based rehabilitation programmes show that the effectiveness of rehabilitation workers depends on certain personal and non professional attributes rather than factors. Such as the level of training and specialization a person has.

Disabled people themselves are a crucial resource.

EVALUATION

An **ongoing process of evaluation** by the members of a community program is necessary if problems are to be corrected and improvements made.

Evaluation is a tool for problem-solving and planning.

Informal evaluation can take place often: the group sits down together once a week (or even for a few minutes once a day) to discuss successes and failures, what seems to be working well, and what does not. Together the group looks for solutions and makes plans. A somewhat more **formal evaluation** might be done at the end of each months and each year.

The PROJIMO team, at the end of each month, makes an effort to fill out an evaluation form that outlines the following information:

- numbers and names of workers involved, the responsibilities of each, hours worked, and pay received.
- number of children seen (new and returning) at the center and in their homes. Also their ages, type of primary disability, and secondary disabilities.
- number of children who stayed at PROJIMO for more than one day, for how long, and with what family members.
- attention received by children and families: hours of instruction or ***therapy,*** number of braces, limbs, wheelchairs, and other aids or equipment made or provided.
- accounting for costs of the above, including what portion was paid by each family and how much was paid by the auxiliary fund (see p. 585)
- summary of financial accounts with list of all moneys gained and spent. . summary of evaluation of individual children by the PROJIMO team and by their parents (This includes a list of children who have made return visits, with comments on their progress and response to suggestions, home therapy, or aids.).
- volunteer help or participation by members of the community (children and adults).
- number and profession of 'special visitors' or visiting instructors.
- new relations or interactions with other rehabilitation centers programs, and communities.
- feedback based on parent questionnaires, what they and their children have gained from PROJIMO, how they feel they were treated, what criticisms they have, and suggestions for improvement.
- outstanding problems and successes in each of the main activities PROJIMO.
- conclusions and recommendations.

To help in the evaluation of PROJIMO, **parent questionnaires** are given to each family at the end of their first visit. Another questionnaire is sent several months later, to learn more about how the child has (or has not) benefited.

The PROJIMO workers are still not happy with the forms and questionnaires they are suing, and have revised them several times. For this reason, we do not include samples here. However, we would be glad to send our forms, such as they are, to anyone who thinks they might help in designing their own.

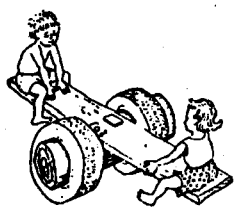
In addition to the monthly written evaluation, at the end of each year the PROJIMO team has an 'evaluation dinner'. The team invites some disabled children, their parents, and some members of the community to participate. The activities of the past year are reviewed, along with problems and successes. The long-range 'vision' and direction of PROJIMO is discussed. Based on this discussion, plans, changes, new activities, and goals are outlined for the coming year.

When families first arrive at PROJIMO, they are given a leaflet which describes the program. It describes or lists:

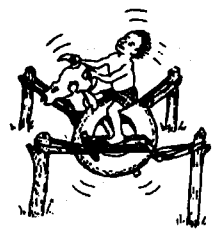


- the reason for the program
- who the workers are
- how the family can help (work that can be done)
- suggestions for donations such as blankets, wood, rope, food
- the services provided
- the disabilities that are attended

This is the way the leaflet starts:



WELCOME TO PROJIMO



Most of us who work in PROJIMO are disabled villagers. We understand the difficulties disabled children face in our society, just as we understand how hard it is for many families to find adequate rehabilitation counseling and services. ***Orthopedic*** aids as well as physical therapy are very expensive. The few free services that do exist reach only a small fraction of the children who need them. Therefore, many disabled children, especially in rural areas, lack even basic rehabilitation services.

We formed PROJIMO to provide friendly advice, therapy and orthopedic aids to disabled children whose families could not obtain, for economic or other reasons, the services that their children need.

Family members as rehabilitation workers

For most disabled children, we believe that the best place for rehabilitation is in the home, and that the best 'therapists' are those who most love and understand the child: the members of his or her own family.

Our goal in PROJIMO is to help you, the parents and relatives, to provide the best rehabilitation and opportunities you can for your child.

Here in PROJIMO we live together as a family. We invite you and your child to participate in our work and activities. We ask you for your suggestions and opinions. We appreciate your assistance with exercises or making aids for your child (or other children), as well as your help in the daily maintenance and work of PROJIMO.

PLEASE HELP US TO HELP OTHERS

FINANCING

It is a goal of many community programs to become as financially self-sufficient as possible. Only when a program does not depend on outside funding can the community and participants of the program have a full sense that "The program is ours. We'rn it. We control it. We make the main decisions ourselves"

Realistically, however, for health programs in general and for rehabilitation programs in particular, economic self-sufficiency is difficult to accomplish. This is especially true if the program aims to serve mainly those who are poorest and whose needs are greatest. The poor earn barely enough to feed and clothe their children, and then sometimes not adequately. The additional expenses of trying to meet the needs of a disabled child may be too much for the poor family to bear, even when the costs are kept low.

The biggest obstacle to economic self-sufficiency of any community program is poverty.

In a country where social injustice causes widespread poverty, it is not fair to expect the poor to pay for more than a small part of the cost of rehabilitation services or aids. Nor is it fair to ask a busy rehabilitation team to try to make their program self-sufficient through separate 'income-producing activities'. (However, 'income-producing activities' can help meet some expenses and prepare disabled persons to work and earn independently. We discuss this on the next page.)

True self-sufficiency of a community service program may only be possible through a process of social change and fairer distribution within the whole structure of the society. Only when enough jobs are available and nearly every family earns enough to be self-sufficient in terms of meeting its basic needs, can program self-sufficiency become a realistic goal. In the meantime, some sort of outside funding, government or private, is usually necessary.

Funding-government?

The major ministries who plan, launch and finance programs for disabled people are:

1. **Ministry of Welfare:** This ministry has perhaps the largest involvement in planning and funding rehabilitation programs such as
   - development of services
   - promotion of technology for aids and appliances
   - schemes to fund voluntary agencies.
2. **Ministry of Health :** Mother and Child Health National Programs on Leprosy, Vitamin A, Tuberculosis, Goiter, Immunization, Poliomyelitis.
3. **Ministry of Human Resource Development :** Programs for integrated education.

4. Ministry of Labour :
   - Work Training
   - Employment opportunities
   - Special employment exchanges
   - Vocational Rehabilitation Centres.
   - Resource Development

NON–GOVERNMENT FUNDING

This can come from a variety of sources including overseas funders, major financial institutions, public sector banks and other service organizations, charitable trusts, voluntary agencies and religious charities.

Overseas Funding

A large number of overseas funding organizations are working in India, funding activities related mainly to integrated rural development. Some of them also support programs for disabled people.

The best know is UNICEF which works closely with the government in prevention, integrated education and community based rehabilitation programs. UNICEF also supports a few voluntary organizations involved in community based rehabilitation programs.

The embassies of United Kingdom, Canada, Sweden. Norway, The Netherlands and Denmark are also involved in supporting some of these programs through their development assistance channels. These overseas donors have different priorities for support. Many of them work through local voluntary organization which are registered bodies with clearance from the Home Ministry, to receive foreign funds under the Foreign Contribution Regulation Act (FCRA).

Some of the major financial institutions and public sector banks in the country provide some funds for voluntary organizations involved in rehabilitation work.

Besides, a few industrial houses from the corporate sector are also involved in supporting rehabilitation programmes. Notable among these are the House of Tata's, which supports leprosy rehabilitation programmes and awareness building activities, Brooke Bond India, which helped to set up an artificial limb manufacturing centre and Goodricke India, which supports work of voluntary organizations involved in rehabilitation of disabled people. Some industries in the public and private sector provide employment opportunities for disabled people by reserving jobs in some categories and by patronizing sheltered workshops run by voluntary organizations. In Titan Watches Limited, for instance, nearly six percent of the employee strength is comprised of disabled workers. NTTF is another organization which actively promotes training and employment of disabled person.

Service organizations like the Rotary, the Lions and the Round Table among others are involved in fund raising for prevention and rehabilitation programmes, apart from private charitable trusts and individual philanthropists.

LOCAL FUNDING

It is also a good idea that a fair part of program costs – if possible at least half – be met within the community. Possible local sources for meeting costs include:

- **Fees or contributions from families served:** Some families will be able to pay more than others. Therefore, the fee should depend on their ability to pay. When families come from outside the community, their ability to pay may be hard to judge. Project PROJIMO has tried an 'honor system' for payment of services. They ask the family to make whatever donation they can afford. So as not to shame the family who gives little, or make proud the family who gives more, each family puts whatever they can in a closed box in the corner. Only the family knows how much they gave.

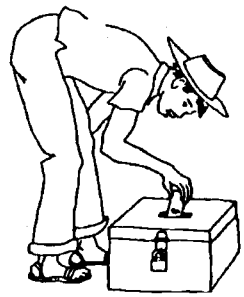
- Service 'in kind' or with work: The community's contribution does not have to be in money. People can donate materials (sand and rock for building), do volunteer work, or provide food and lodging. All this reduces program costs.

- Income-producing activities: Production of things for sale is another way to help meet program costs. It also provides skills training for older children and temporary workers in the program. We will discuss this further on p. 620

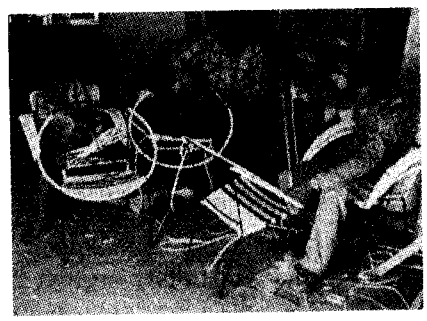
  Although production of items for sale may not bring in much money, the extra income may mean that more disabled persons can be employed on the program staff. They can learn rehabilitation skills and at the same time learn income-producing skills, both of which they may put to good use.

  Experiments on these lines are being tried out by different voluntary organizations such as Life Health Centre for the Handicapped, Madras (Toy making, printing press, power laundry) , Shree Ramana Maharishi Academy for the blind, Bangalore (dairy, poultry, dishing, horticulture, semiculture, computer training) and Association for the Welfare of the Handicapped Kozhikode (printing, garment manufacture, training in secretarial practice, medical technology, ...aids and appliances.

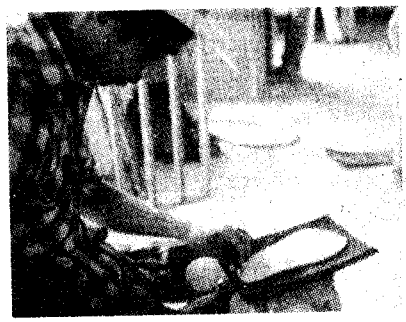
  Some programs that are run for and by disabled persons have succeeded in meeting a large part of their costs through production and sale of goods. For example, the Centre for the Rehabilitation of the Paralyzed in Bangladesh creates a wide range of orthopedic and hospital equipment, much of which they sell to orthopedic hospitals (see p. 626.) The Disabled Revolutionaries of Nicaragua has succeeded in developing a nearly profitable business out of making low-cost, rough-terrain wheelchairs. In Paraguay, a group of disabled workers has also made wheelchair making a small but profitable business.



Nobody knows how much the individual family gives.



Weaving of chairs with plastic ribbon on a metal frame brings in income and provides skills training (PROJIMO).



Sandal making produces income and teaches a skill for later self-employment (PROJIMO).

NOTES

CHAPTER 52

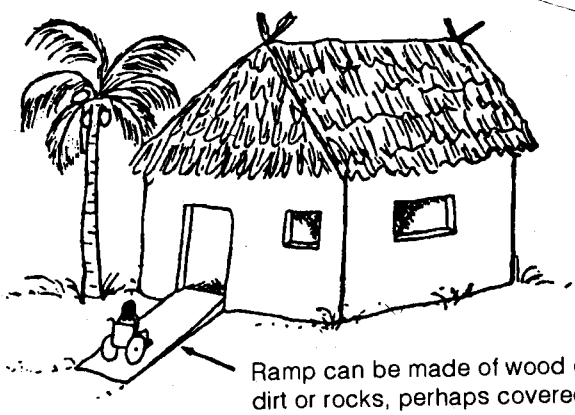
Adapting the Home and Community

ADAPTING THE HOME

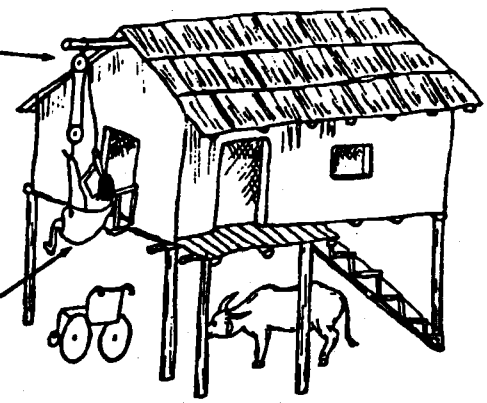
The kind of **adaptations** needed in the home will partly depend on the **kind of disability** a child has, the **severity of disability**, and the **age** and *size* of the child. Adaptations for a child who is blind are very different than those for a child who is **paralyzed** and uses a wheelchair. A child who is completely dependent will need aids and adaptations to help the family care for him and move him–especially as he gets older and heavier. However, the disabled child who can do a lot for herself may be helped by adaptations that make self–care and work in the house easier.

The kinds of adaptations needed will also depend on the **local living situation, style of house** and **customs**. For example:

A simple ramp may work well for a wheelchair entrance to a house 'near ground level'



Ramp can be made of wood or of dirt or rocks, perhaps covered with a thin layer of cement. For details, see p. 591.



A system of ropes and pulleys may be the best way for a person with strong arms to lift herself without help to a 'house on stilts.'

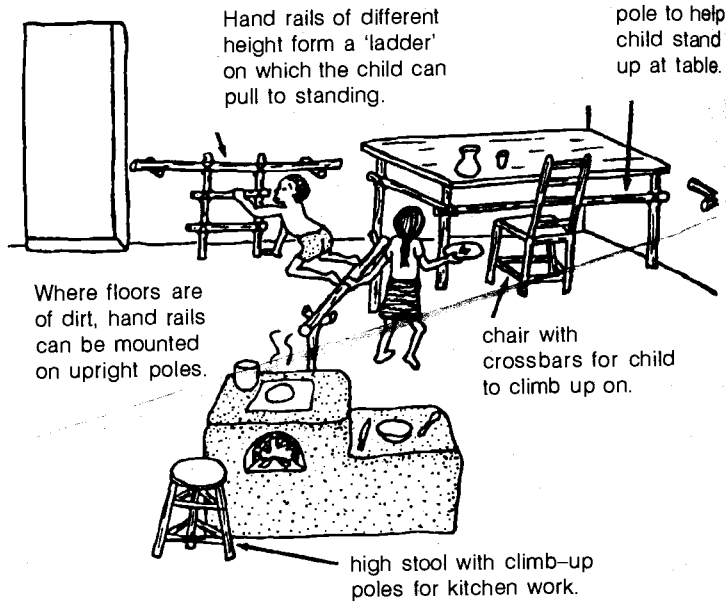
The 'lift' can be made with a platform so that the whole wheelchair can be lifted. But if the house is small and people cook and eat at floor level, it may be best to leave the wheelchair outside.

Adaptations for the child who is learning to walk and balance

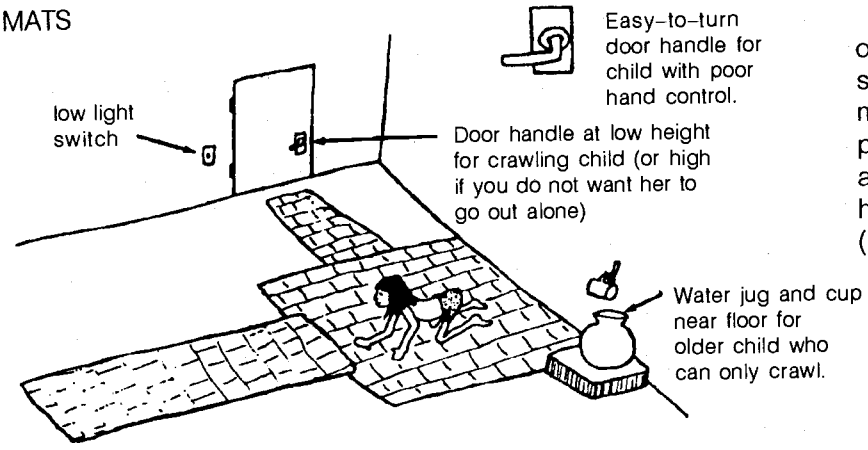
HAND RAILS

These can be fixed to the walls and furniture. If necessary, pathways with rails can be put up so that the child can walk with support almost anywhere in the house, and also outside to the latrine (toilet) or garden (see p. 617).

Before attaching hand rails firmly, test the child with a temporary rail at different heights to find out what works best. As the child grows, you may need to place the rails higher. Or you may want to remove rails little by little to help the child improve her balance and walk more independently.



MATS



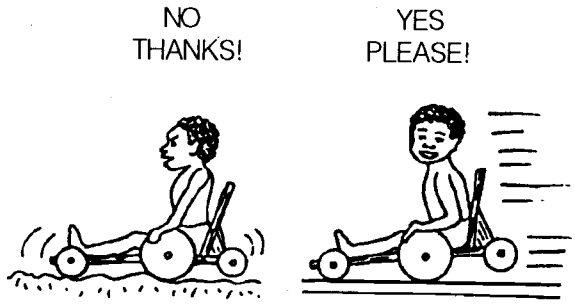
For the child who only rolls or crawls, some kind of straw mat or rug will help protect her knees and skin, and will help her stay cleaner (if floors are of dirt.)

The 'model home' in PROJIMO is a guesthouse. It has features that make it easier to care for a disabled person, or for a disabled person to care for herself and do housework. Visiting families can find out what is useful for their child and can adapt their own home. Here PROJIMO workers split wild cane to make screens to keep out the animals.



Home adaptations for wheelchair riders

FLOORS



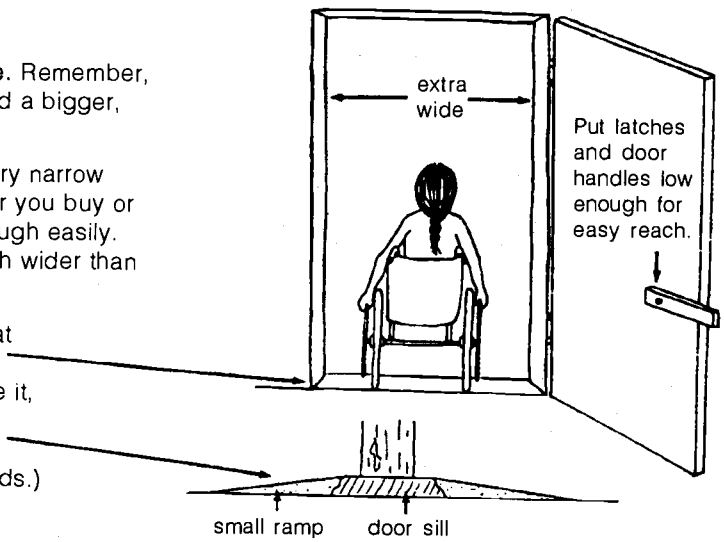
For almost any disabled person– but especially those who use wheelboards or scooters with small wheels, the floor should be as **smooth and firm** as possible (but not slick or slippery). Packed, smoothed clay–and–cow–dung surfaces (as used in India) work well. Cement is even better for long–lasting use of a trolley or wheelchair. Although expensive, a smooth cement floor makes getting around a lot easier.

DOORWAYS

Make all **doorways extra wide.** Remember, your child will grow and may need a bigger, wider wheelchair.

In a house that already has very narrow doorways, be sure the wheelchair you buy or make is narrow enough to fit through easily. Most commercial chairs are much wider than necessary, especially for a child.

Try to avoid any rise or bump at the doorway. If it already has a raised sill and you cannot remove it, build a small ramp to go over it. (This will be of special help for children with weak arms and hands.)



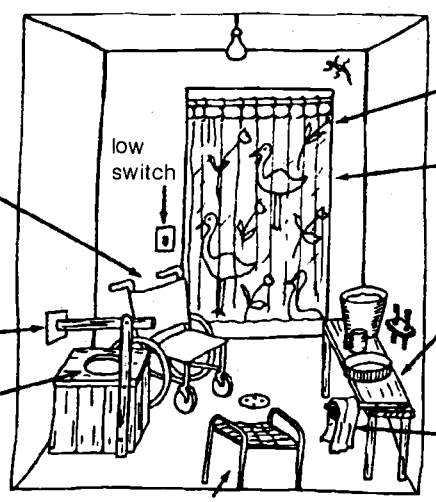
BATHROOM OR OUTHOUSE (LATRINE)

Be sure the room is big enough for a wheelchair to turn around in easily.

A wheelchair without armrests or with a removable armrest is best for transferring to the toilet.

hand rail on far side from wheelchair

toilet seat the same height as seat of wheelchair



wide doorway

For a wheelchair rider, a curtain is often easier to open and close than a door.

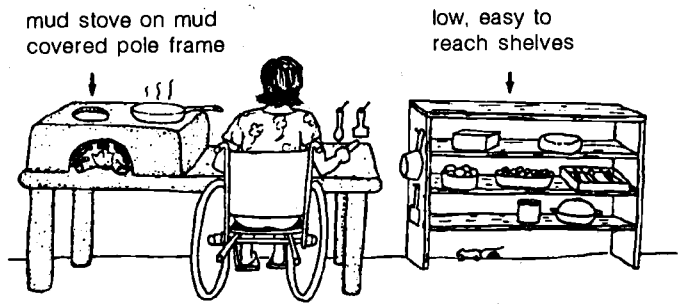
washstand at height just above knees of wheelchair rider

towel on low rack

bathing stool same height as wheelchair, with metal frame and woven plastic or rubber strips of car inner tube

KITCHEN AREA

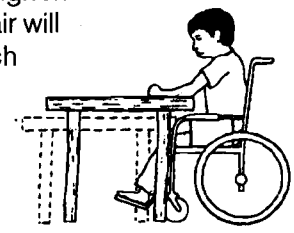
The stove, work areas, and tables should be as low as possible, but high enough so, that the legs of the wheelchair rider can fit under them.





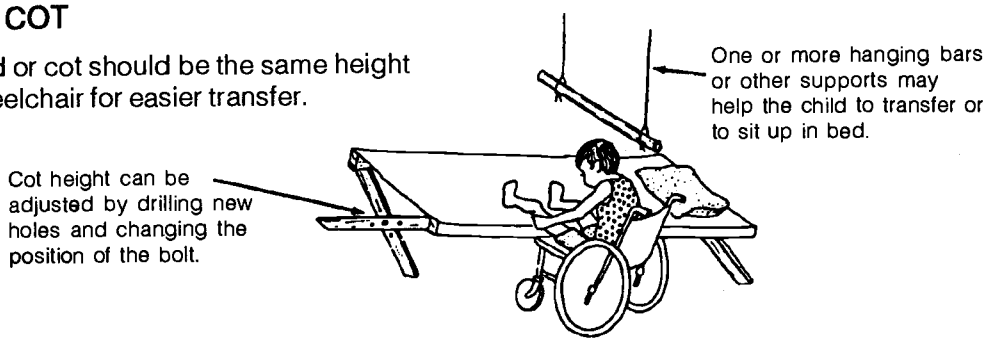
The cooking and eating area in the model home at PROJIMO has a lot of adaptations.

CAUTION: If the wheelchair has high fixed armrests, the tables and oven will have to be higher. Or the wheelchair will have to approach from the side, in which case the table should be lower.

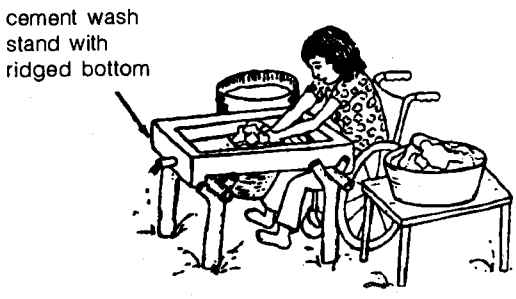


BED OR COT

The bed or cot should be the same height as the wheelchair for easier transfer.



WASHING AREA (outdoor)





Outdoor washing area at PROJIMO — designed for work from a wheelchair.

IMPORTANT: Before building fixed-height stoves, tables, and wash areas, **set up something temporary to figure out what works best.** Remember that the child is growing, so try not to make things too fixed or permanent.

ADAPTING THE COMMUNITY

In many villages, disabled persons have a hard time going places because streets or paths are rough,rocky, or sandy. Also, there may be high steps for getting into stores, the cinema and even the town meeting hall,school, and health center.

A village rehabilitation program can encourage the villagers to make it easier for disabled persons to go places and to participate in community activities.

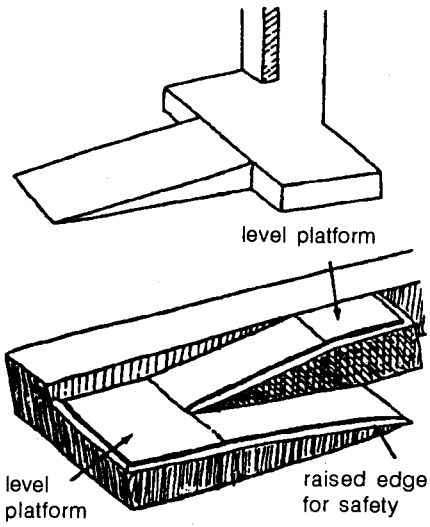
For example, ask storekeepers to build ramps so that wheelchairs can enter their stores. Disabled persons and their families can promise to give their business to those who cooperate in this way, and if necessary, can boycott (refuse to buy from) those who do not.



A Cycle Rickshaw made by people in village Anekal near Bangalore for transporting disabled children. The children have much more space to sit and feel more secure. The design is a combination of a cycle rickshaw and a Tanga (horse pulled cart)
Photo : Sewa-in-Action.

RAMPS

The more gentle the slope of the ramp, the easier it is for a wheelchair rider to go up it.

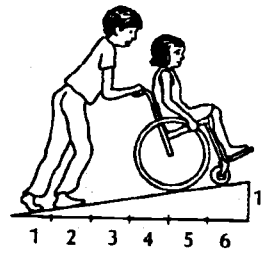


One or more ramps can be put parallel to the edge of the raised area. Be sure to leave large level platforms for turning.

Addition of hand rails will add safety and make going up ramps easier for persons who walk with difficulty.

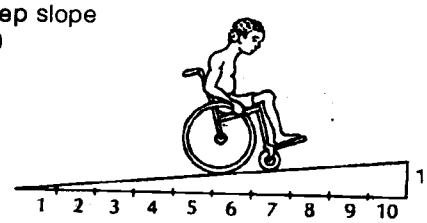
HOW STEEP YOU MAKE THE RAMP DEPENDS IN PART ON WHO IT IS FOR.

Very steep slop of 1 to 6



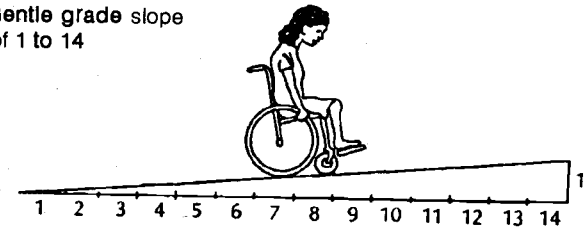
Only possible with electric wheelchair or with help. Rarely possible for rider alone. Chair may tip backwards.

Fairly steep slope of 1 to 10



Possible for riders with strong arms:strong paraplegics.

Gentle grade slope of 1 to 14



Possible for average riders and strong quadriplegics. This is the best slope for public buildings and rehabilitation centers.

Improvement of walkways and trails

Community work parties or groups of schoolchildren can organize to help fix up **smooth,hard-packed pathways** through the village so that crutch users and wheelchair riders can go places more easily.

Also, if possible, easy-to-use pathways can be set up so that disabled children and adults can get to play areas, bathing areas, and family work areas.



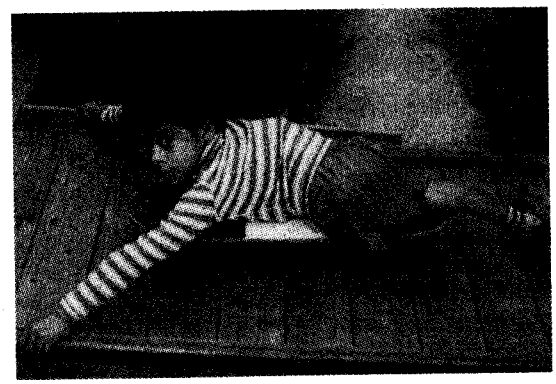
HAND RAILS (or ropes)

When placed along steep trails, these may permit children who are blind, who have balance problems, or who have difficulty walking to reach areas such as swimming or fishing holes.

In one village a rehabilitation team together with some of the village children improved the steep trail down to the river, so that disabled children would have a chance to play and swim.



The health workers of Project Piaxtla built this ramp so the wheelchair riders could come into the clinic easier. (Photo:John Fago)



A narrow wood ramp with side boards lets this child pull himself up it on his skateboard.

An adaptation is rarely a one time thing. The need for adaptations changes with the changing circumstances , age, expectations of the child, and his family and many other factors. Here, we give an example of how a team of rehabilitation workers and the family of a severely quadriplegic boy, worked towards different adaptations to meet the different toiletting needs of the growing boy.

Ajay lives in Ballabhgarh, a small township on the outskirts of Delhi. He was born a severe quadriplegic. As he grew older, even though he was a bright boy, there were very few tasks that Ajay could do.



The toilet in Ajay's house was shared by 12 family members.

People had to climb 2 steps to get to the bathroom. They had to squat to go to the toilet. There was a handpump outside, which was the source of water. Ajay could not sit independently. Nor could he climb stairs. He had to be carried there by his mother and was totally dependent on her.

As he grew older, it became increasingly difficult for his mother to carry him up and down the stairs all the time.

Photo: Spastic Society of Northern India



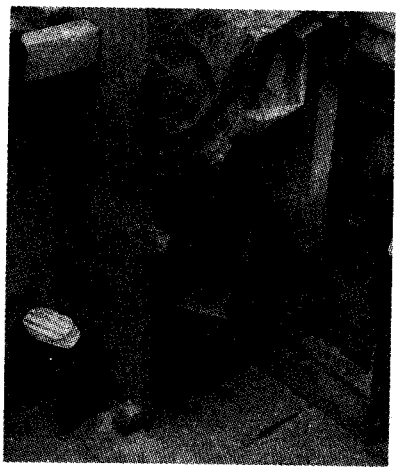
When he was 8 years old, Ajay's mother asked members of the Spastic Society to help her find a solution to Ajay's problem. A little research revealed that all the boys of the neibhourhood went to the toilet outside their houses. They squatted above the drain that ran outside their houses. This was a culturally acceptable practice.

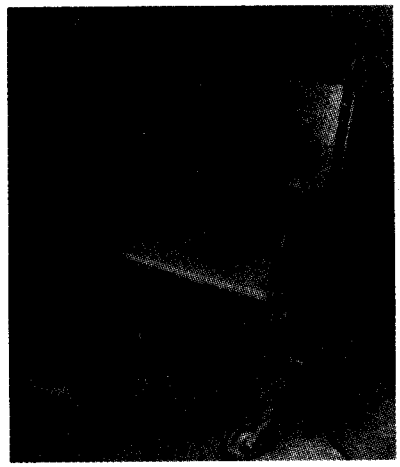
So a potty chair was designed for Ajay which could be put outside on the drain. All his mother had to do now was to take Ajay on the wheelchair to his potty chair. She would then help him transfer from the wheelchair to the potty chair. Later, she would help him wash. This was much simpler for her and it also gave Ajay the feeling of being 'one of boys'!

An old wheelchair was converted into a potty cum bathing chair. The seat was made of fibre glass even though it is slightly more expensive than other materials. Fibre glass lasts longer and will not rot like wood if water is poured constantly on it.

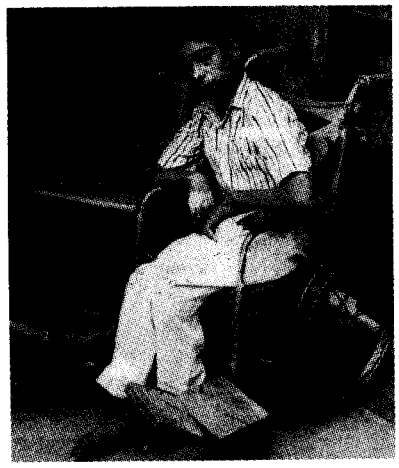
A drain with a slope downwards was constructed in the corner and this led to the drain outside the house. So after Ajay had performed, his mother could flush the stool out into the drain outside with some water.

A bucket full of water with a mug is put next to the wheelchair when Ajay needs to have a bath. The soap, toothbrush and other toiletries are put on wooden shelves at a height that he can reach while sitting on the wheelchair. Ajay is now quite independent while bathing, brushing, or going to the toilet.





As he grew older however, Ajay started feeling the need for more privacy. A solution had to be found now within the house. After much searching and thought, the rehabilitation team along with Ajay's family found this solution. In the corner of the courtyard, they dug in a wooden pole, put up a tin shed with a plastic curtain on one side. This was to serve as Ajay's bathroom.



He only needs help to transfer from one wheelchair to another.

Photo: Spastic Society of Northern India by Avijit Kishore

CHAPTER 53

Love, Sex, and Social Adjustment

In the village of Ajoya, the home of Project PROJIMO, disabled young men and women happily go to dances and outdoor movies together. They are not ashamed to let people know that they have a close or loving relationship. Some of the disabled young persons who have grown to know and care for each other through the Project have married and now have children.

All this is fairly much accepted as natural and normal and 'right' by most of the local villagers.

But things were not always this way. A few years ago, when PROJIMO had just begun, many people believed that a ***severely*** or even ***moderate disabled*** person should not and could not have a relationship, get married, or have children.

I remember one evening in the spring, a few years ago. An old woman watched a group of young couples listening to guitar players at the village square. One young man, who had a clubbed foot and used a cane, stood close to a young woman in a wheelchair. When the musicians started playing a romantic song, the disabled couple gently put their arms around each other. The old woman was shocked. Angrily she pointed to the pair and cried, Isn't that disgusting! People like that have no right to behave like that! It's not natural! They're cripples!"



Disabled persons and their families must educate the public about their rights.

When PROJIMO first began, unfortunately the villagers mere not the only ones who thought the disabled persons should and could not get married or have loving relationships. Many disabled young people half-believed it themselves, and in their personal lives were often depressed, frustrated, or confused. While society told them one thing, their hearts and their bodies told them another. Most believed they could never be attractive to a member of the opposite sex. Yet through adolescence, they felt increasingly attracted. Many had serious doubts about their own sexual ability. Some had discovered that they did, infact, have fully developed feeling and functions. But they had no acceptable way to express them.

Some visiting advisers to PROJIMO were older disabled persons who had learned to understand their own feelings, had married, or had formed loving relationships. Slowly the disabled young people at PROJIMO began to accept their own desires, needs, and dreams. More important, they began to discover they were not so alone, not as different from other people, as they had thought. Above all, they discovered that they were attractive to other persons. Soon the romances began.

At first things sometimes got out of hand. The bottled-up feelings of the young people came flooding out. There were occasional mistakes and abuses. When the disabled group discovered that the rules society had set for them were unfair, often their first response was to break the rules recklessly. But then, faced by the sometimes cruel results of their own hurry, passion, and inexperience, they discovered the need for a few precautions and guidelines determined by the group. They had been hurt often enough themselves not to want to cause additional hurt. And so, little by little, the PROJIMO team members have discovered their ability to live fuller lives and have more complete relationships than they had previously believed possible. Also, little by little, the local community has begun to accept this. For the first time, romances have begun to develop openly between on-disabled and disabled possible. Also, little by little, the local community has begun to accept this. For the first time, romances have begun to develop openly between non-disabled and disabled villagers. A new level of awareness and acceptance is slowly being achieved.



Conchita, who is paraplegic, was sure she could never marry. She came to PROJIMO for rehabilitation and later became one of the workers. She is now happily married to one of the able-bodied villagers.

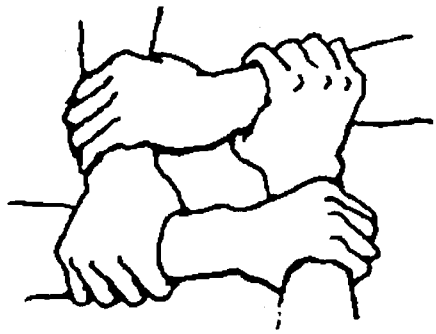
The personal and sexual needs of young persons

Every child, whether disabled or not, has the same basic needs for food, protection, and love. The child who is treated consistently with love, respect, and understanding has a greater chance of becoming a loving, and understanding adult.

Every child has a need to be touched, held, and caressed. Small children find pleasure and learn about themselves by exploring and touching different parts of their bodies. A child whose disability makes touching and exploring her body more difficult, may have an even greater need than other children to be held, hugged, and caressed.

Most societies have rules and taboos that attempt to limit and govern sexual behaviour. And within most societies, young people (and old) usually find ways of getting around some of those rules, usually more or less secretly.

The best answer to sex education may be to look for informal and unsupervised ways for disabled adolescents to spend time with and share the secrets of other adolescents.



LOVING RELATIONSHIPS, MARRIAGE, AND FORMING A FAMILY

It is important that disabled persons and everyone in the community realize that most disabled persons are capable of getting married and having children. Except for a few ***inherited disabilities***, the children born to disabled parents have just as great a chance of being normal as do children of non-disabled parents.

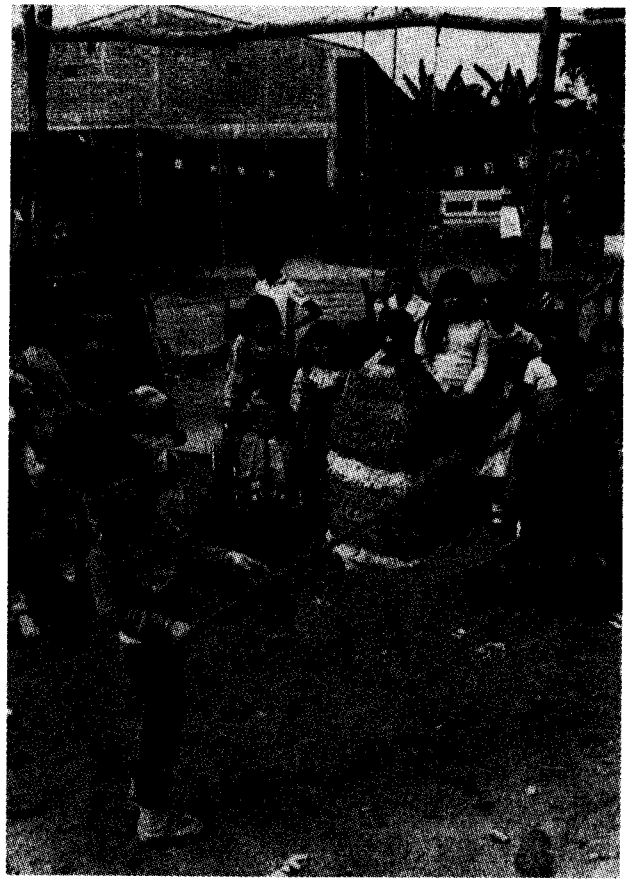
For most disabled persons, a close, loving partnership is possible. This is true even when the disability makes having children unlikely, as in some men with ***spinal cord*** injury. Persons who have no feeling in their sex parts can discover sexual satisfaction through meeting of lips or other parts of the body that feel. If the couple want children, perhaps they can adopt them.

In some societies, nearly everyone is expected and able to marry, including disabled persons. But in cultures that put great importance on an 'ideal' or complete ***physical*** appearance, it may be difficult for the disabled person to find a partner. The biggest barrier is sometimes the feeling by the disabled person that he or she can never be attractive to anyone. To overcome those feelings, disabled person can sometimes advise one another. Those who have overcome their own fears of unacceptability and have formed loving relationships can do much to help others realize that inner beauty and gentleness of spirit can also make a person attractive.

Often it takes someone with a disability to see beyond the outside of another disabled person to the unique qualities inside. So it often happens that disabled persons take other disabled persons as partners–although their disabilities may be quite different. However, as disabled persons gain greater acceptance and participation in the community, loving relationships and marriage between non-disabled and disabled persons become more common.

Often there are not many chances for disabled young persons to get to know and become close to other young persons. Therefore, such opportunities can and should be sought or arranged. The types of opportunities and how they can be arranged will of course differ from one community to another.

Chances should be provided for disabled young people, even in wheelchairs, to go to ceremonies, dances, and public events that other young people attend. A community rehabilitation program can arrange games, parties, and other activities to which both disabled and non-disabled young people are invited, and in which they can participate equally.



A community rehabilitation program finds enjoyable ways to bring disabled and non-disabled children together. Here the village children have been invited to the birthday party of a disabled child. They take turns, blindfolded, trying to break a 'pinata' (a papier-mache toy filled with candy and nuts). (PROJIMO/Richard Parker).

The need for full integration

It must be remembered that opportunities for a close, loving relationship are only one aspect of leading a full, accepted and participating life in the community. The more that can be done to bring about greater integration and participation of disabled persons in the life of the community, the more everyone will learn to look beyond a disability and see the person. When this happens, it opens up many new possibilities.

Birth control

Disabled girls and boys should be given the same information and opportunities to avoid unwanted pregnancy as non-disabled young people. Making such information and methods available may be of special importance for participants in a self-run community rehabilitation program. (For different methods of birth control, see *Where There Is No Doctor,* Chapter 24.)

The mentally retarded child and sex

Mentally retarded children, like others, as they grow up take increased interest in sex. In fact, they may take more interest in bodily experiences because opportunities for other activities are more limited.

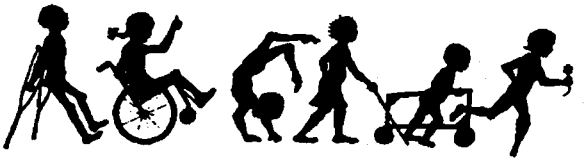
Because the complex messages that the retarded child gets from other people are often confusing or contradictory, the child may develop unacceptable patterns of ***behavior***. Often parents do not know how to handle this. For example, a mother may be afraid to take her mentally retarded boy with her to the market because he tries to touch every girl he sees.

It is important that retarded children are helped to understand clearly what behavior is acceptable and what is not, and where. To accomplish this, a **behavior approach to learning** can be used. The family can consistently reward good behavior and carefully avoid giving the child special attention or in any way rewarding bad behaviour. This approach is discussed in Chapter 41. In children with behavior difficulties, if possible, the family should start using a behavior approach to learning long before the child grows up sexually. The younger the better.

A common mistake is to pretend that mentally retarded young people do not have a need for loving personal relationships The need exists, and if unanswered, can lead to difficulties both for themselves and for others.

In most communities, it is very difficult for the retarded person to have a close, loving relationship. In some countries, programs arrange for retarded persons to live together in special homes or to come together for social activities. As a result, some of them form couples, and sometimes marry. (However, marriage is not a cure for mental retardation as same may believe.)

Trying to protect retarded girls against sexual abuse, and undesirable pregnancy, and at the same time respect the girls' rights, can be difficult. Some programs try to solve the problem through sex education, or by providing retarded young women with birth control methods to prevent pregnancy. Check with your local health worker to see what birth control methods are available and acceptable in your area.



Marriage and family

In countries where the disabled have achieved greater acceptance and involvement in the community, an increasing number of disabled persons, including some with fairly severe disabilities, are getting married and having families of their own.

The ability of a married disabled person to bring up a family depends a lot on economics. Thus, an effort to help young disabled persons learn the skills necessary to work and earn a living or maintain a home is an important part of the preparation for marriage and family.

Sex education

On the average, disabled children begin to mature sexually around the same age or even a little earlier than non-disabled children. Girls may begin to have monthly bleeding (menstruate) as early as age 11 or 12 (or earlier or later). Boys begin to release semen at age 12, 13, 14 (sometimes earlier or later). Often these new bodily functions take the child with confusion or even guilt unless he or she is informed about their naturalness and purpose.

Because disabled children often do not have the same opportunity to mix with other children in an unsupervised way, they often miss out on one of the most common forms of sex education: children's games, jokes, stories, songs, and private discussions. Therefore, older persons should make a special point to share basic 'facts of life' with these children in a relaxed, trustful way, inviting questions and answering them honestly.

Equally important of course, is to make arrangements for disabled children to mix with, play with, and join in the secrets of other children.

The need to accept a wide range of sexual behavior

Opportunities for close relationships may not arise as often or as easily for disabled persons as for non-disabled persons. Many of the standard ways that 'boy meets girl' may not be open.

It is therefore not surprising that some disabled people enter into less common types of love relationships–sometimes a younger person with an older person, sometimes 2 members of the same family or of the same sex, or 2 persons from different castes, races, social levels or other social groups between which relationships are not locally approved.

Before condemning such a relationship, it is important to consider what benefit or harm it is providing for each of the partners. If both partners have entered the relationship willingly and seem happier and more whole because of it, those concerned should perhaps be supportive–even if the relationship is not socially approved.

Many groups and organizations of disabled persons are outspoken in defending the rights of persons to live in ways that are different from the norm, as long as no one is being forced or hurt. They know from personal experience, that society is often cruel and unfair in its treatment of those who happen to be 'different. So they try to take the lead in the re-education of the community toward a more flexible and accepting attitude with regard to human variation.

On the other hand, disabled children or young people are sometimes in a position where they can more easily be taken advantage of or abused. The very loneliness of some disabled young people or the innocence of the retarded child often makes them easy targets for abuse. Necessary precautions need to be taken.

What is important when 2 people live together is not who they are, but that they truly care for and respect each other.

CHAPTER **54**

Education

At Home, At school, At Work

Guided learning to help a child gain skills and understanding for meeting life's needs is called 'education'. In Chapter 35 to 44 we talked about ways to help disabled and delayed children learn to control and use their bodies and minds, and to master early basic skills for daily living. But as a child grows up many additional skills and knowledge are needed.

For nearly all children, **education begins in the home**. For some it continues in school; for others in the fields, in the forest, at the marketplace, on the riverbank, or in the streets.

In the cities of most countries, a school education has become almost a basic need for getting a job or being accepted by society . In many villages and farming communities, however, 'book learning' still is much less important than the skills children learn through helping their families with daily work.



For many children in rural areas, the most important parts of their education do not take place in school.

In some rural areas, therefore, it may be a mistake to think that 'every child' should go to school. For the child who is ***physically*** strong but ***mentally retarded,*** schooling may be a frustrating and unrewarding experience, especially if no 'special education' is available. The child may be happier and learn more skills for meeting life's needs by helping father in the fields, or mother in the marketplace, than by going to school.

However, for some retarded children in rural areas, schooling can be important. If the teacher and other children can be helped to understand the special needs of the child, treat him with respect, and give him encouragement, the slow learner may benefit greatly from school, both educationally and socially.

Whatever the case, it is important to consider the local situation carefully. **Do not just follow the recommendations from the outside about the importance of schooling.** Some school situations are better and some are worse than others. So before deciding for a particular child, look carefully at the good and the bad things about the local school and consider the other choices.

For the physically disabled child in the rural area, schooling may be especially important – more so, perhaps, than for able-bodied children. Physically disabled children often cannot do hard physical farm work as well as the able-bodied. Therefore, they need to learn skills using their minds, so that they can work or take part in community activities. It may help them to go as far in school as possible.



In a village, skills learned through schooling can be more important for the disabled person than the non-disabled.

Regular school or special schools?

Today, leaders in rehabilitation generally feel that **disabled children should attend the same schools as other children, whenever possible**

For mildly or moderately disabled children this should not be a big problem, if the parents, school director, and teachers cooperate. In some communities, however, and especially in rural areas, parents may not even think of sending their disabled child to school. They may fear that their child will be teased or have too hard a time. And in some places, school directors or teachers refuse to accept even a moderately disabled child with a quick mind. Distance and other problems getting to school also add to the difficulties.

Education For All

Wherever possible, try to overcome these problems. Rehabilitation workers can talk to teachers, parents and other school children and try to work out the best situation. At times parents of disabled children may need to organize and put pressure on the schools and governments to change their policies. *In the large cities there have been many instances when parents of normal children have refused to let their children study in schools with other disabled children. Often this is because they do not know much about disability. In India, till quite recently, the education of disabled children was the responsibility of the department of Welfare rather than the Department of Education. Therefore despite the government policy of "education for all" disabled children were often left out of the mainstream of education.

*Even non-disabled children are in some ways often damaged by school, even as in other ways they are helped. For an excellent critical analysis of public school in the social context, see *Letter to a Teacher* by the schoolboys of Barbiana. These rural Italian boys declare that "School is a war aginst the poor" (see p. 773.)

The Scheme Of Integrated Education For Disabled Children

The new education policy of the 1986 attempts to change all this. It stresses the need for equal educational opportunities, particularly for those children with special needs and more importantly to integrate children with physical and mental disabilities with the general community as equal partners.

The Central Government has also sponsored a scheme for the integration of disabled children in general government schools all over the country. Although the scheme was launched in 1974 it was shifted to the Department of Education only in 1982.

Under this scheme, the Central Government gives 100 per cent financial assistance to State Governments, Union Territory administrations and voluntary organizations to create the necessary facilities in general government schools for the integration of children with disabilities. The grant includes money for the training of teachers, setting up of resource rooms, carrying out assessments of disabled children, removal of architectural barriers in schools, and the production of any special material needed for disabled children.

The disabled child herself is given an allowance for travel, books, stationary, uniforms and any special equipment or assistance she may need for her studies.

Each State or Union Territory is free to accept or reject the scheme. At present, it is being implemented in some schools of Andhra Pradesh, Bihar, Goa, Gujarat, Haryana, Himachal Pradesh, Jammu & Kashmir, Karnataka, Kerala, Madhya Pradesh, Maharashtra, Mizoram, Andaman and Nicobar Islands.

At the moment only children with mild disabilities are eligible for integration under the scheme. However, there is now a move to include more severely disabled children also. *(For further details write to National Council for Education and Research Training (NCERT), Aurobindo Marg, New Delhi-110 016.)*

Project Integrated Education For The Disabled (PIED)

The Project Integrated Education for the Disabled was launched in 1987 by the National Council for Educational Research and Training (NCERT) with assistance from the Ministry of Human Resource Development and UNICEF. The project aims to demonstrate that ***most*** disabled children can be educated in general schools and that the general education system can and ought to be prepared for this. It attempts to develop area specific strategies for the education of children with disabilities.

The PIED is being implemented in one block each of the states of Madhya Pradesh, Maharashtra, Nagaland, Orissa, Rajasthan, Haryana and Mizoram. All the eight blocks are different in terms of geographical features, the number of people living within a particular area, the social and economic development levels of the block and the availability of facilities for education and women and child development. All the selected blocks are in remote rural areas.

To develop educational resources within the community, all the teachers of schools within the block were given a week long training to help them detect disabled children in the community and look after their special educational needs within the school system. About 10% of the teachers were given a further six week training while 8-10 teachers are given a one year intensive training to work with children having different disabilities.

Each of these multi-category teachers works at a special resource centre which is situated within walking distance of a group of schools. This way, the teacher is able to maintain constant close contact with the disabled children and their teachers in these schools.

The multi category teacher works as a resource person, training children in special areas such as braille, mobility training, speech and language training etc. The teacher also advises the general teacher in schools and parents on aspects of integration. Since most of the teachers who are trained are from within the community, they are able to understand and solve any problems that might come up in the integration of a disabled child in the general school system.

The PIED has worked specially well in the state of Mizoram where nearly all the disabled children of Khazawl block are now coming out of their seclusion to study with other children in general schools.

Special Schools

For more severely disabled children, attending regular schools often may not be possible, at least as schools, exist today. Yet, sometimes if you talk with the teachers and other children, they will become more understanding and make arrangements.

For example, there is a boy with spina bifida who lacks ***bowel*** control and therefore never went to school. But after his parents talked with the teacher and schoolchildren, an agreement was reached. Now the boy goes to school. When he has an accident in his pants, he quietly gets up and goes home to bathe and change. (Fortunately his house is very near the school.)

Children with developmental delay get a head start in a preschool program near Bangalore, India.

In case some disabled children cannot attend regular schools other alternatives can be thought of. For example, there are special schools with **'special education'** programs. But they are very few in number and unevenly scattered throughout the country. Most of these schools are in the cities. Special schools are also expensive to set up and run. Increasingly now, these schools are being seen as training grounds for disabled children to acquire the basic skills needed for integrated education. They can also function as extremely valuable resource centres for other schools wishing to set up facilities for disabled children.

PIED Problem Solving

The implementation of PIED has thrown up some very simple and easy ways of solving problems that come up in integration in schools in remote rural areas.

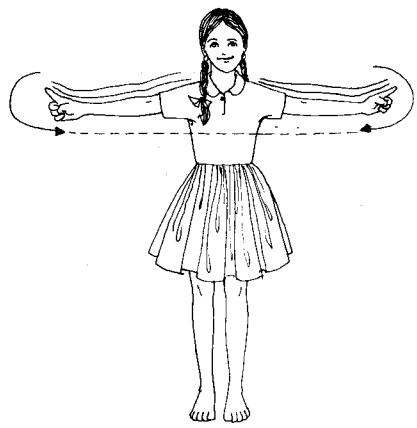
It has also sparked off a lot of government and community action. In one area, anganwadi workers took the initiative to work with the project in the early identification and intervention of children with disabilities. In response the NCERT designed a training program to train them to do the job.

Also it is often impossible to get trained doctors, psychologist and other professionals to come and do regular assessments of disabled children in remote small areas. The PIED faced this problem. So a solution was found. The Special Education team of the NCERT has now prepared a booklet, the ***Functional Assessment Guide*** which can be used by teachers in such areas to detect and assess disabilities amongst the children they teach and the children in their community. The guide contains several easy tests and games the teacher can involve the children in.

Here is one example for testing field of vision from the book.

To test field of vision you can play this game.

1) Ask the child to stretch out her arms behind her shoulder and to point the forefinger up, closing others in a fist. Ask her to move her arms forward until she can see the finger. Note the position from where the child can see her finger (angle of visual field).



The ***Functional Assessment Guide*** is available from the Special Education Unit, NCERT.

Self Help Groups

In the rural areas, with few exceptions, there are no special education programs. However, parents of disabled children may be able to organize and form their own special education programs. The group helps each child to learn at her own pace and in her own way. An example of this is the ***Self Help Groups*** formed by parents in villages near Bangalore. These self help groups are formed with the help of **Sewa-in-Action** a voluntary organization working in these villages.

A self help group is a multipurpose disability centre run by parents of disabled children. It acts as a nodal point in assisting families to develop a range of services and facilities that are relevant to their immediate needs. As part of its activities, the self help group assists in educating children with disabilities who are not in school. Parents pool in their resources to prepare their children for integration into regular schools in the villages. They also act as resource centres for disabled children who are already in schools.



Learning in a Self Help Group. Children with developmental delay get a head start in a pre-school program, India. Photo: Sewa-in-Action

Home Based Programs

Some children however may be so severely disabled that they may not be able to attend even self help groups. In this case some rehabilitation programs have started systems of home based training and study. Parents and their children may come at regular intervals once a week or fortnight or a month to a community rehabilitation centre and take home programs suited to the individual needs of their children to their homes. Volunteers will also visit the homes to help and work out education programs that can be done in the home.

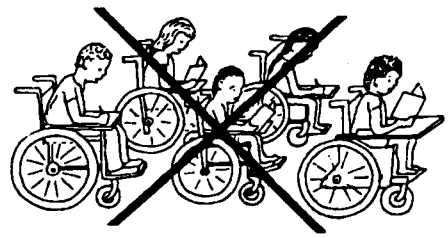
Children who do go to school, either non-disabled or disabled, may be able to teach the severely disabled children at home after school. A community rehabilitation program can also include a study program for disabled children and youths.

This book does not cover the details and methods of special education. It is important that the methods used be adapted to the local customs and situation-not just borrowed from Europe or the USA, as is often done. An excellent book on Special Education For Mentally Handicapped Pupils, by Christine Miles has been developed for the program in Pakistan, and has many ideas for adapting to the local culture. (see p. 772)

Meeting the special physical needs of children at school

When physically disabled children are in school or studying, it is important to remember their special needs, and try to meet them.

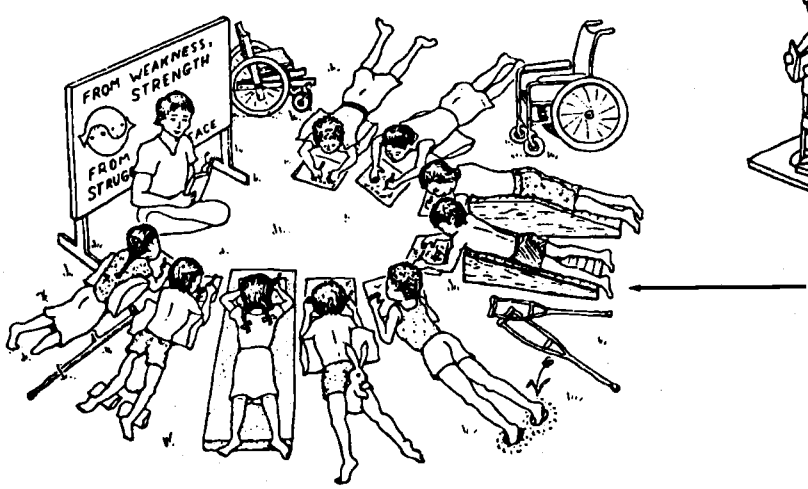
For example, children who cannot get up and run around should usually ***not*** spend all day sitting in a wheelchair. This tends to lead to ***contractures***, swollen feet, weak leg bones, ***spinal curve***, and other deformities.



So try to arrange for the children to spend at least part of the day with their bodies in a straight position.

Part of the day this can be done in standing frames (but usually not for more than half an hour at a time).







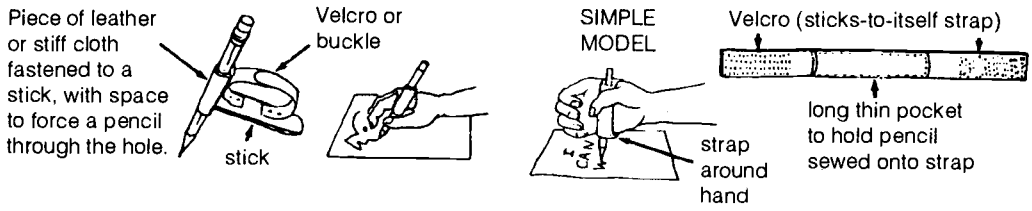
And part of the time it can be done lying down, either on the floor, or on 'wedges' or mats that permit better positioning and use of the hands and arms.

For design details, see pages 695 to 699.

AIDS FOR READING, WRITING, AND DRAWING

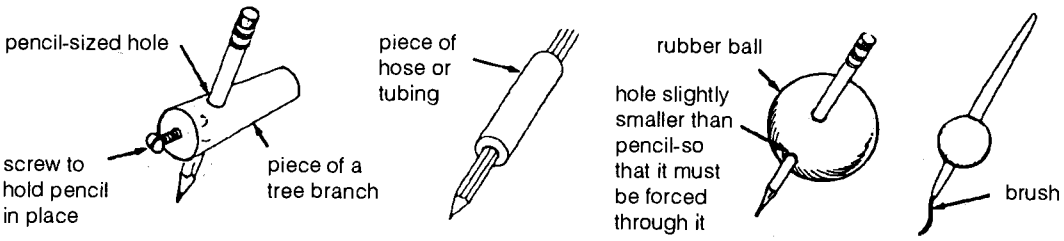
PENCIL HOLDER FOR A WEAK OR PARALYZED HAND

For children who have difficulty holding a pen, pencil, or brush, or turning the pages of a book, you can think of all sorts of *adaptations*. Here are a few examples:



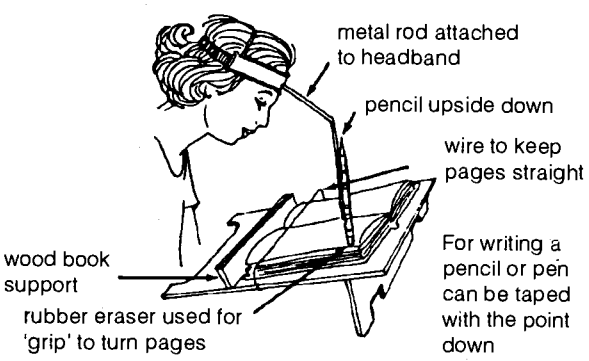
AIDS FOR HOLDING PENCILS, PENS OR BRUSHES

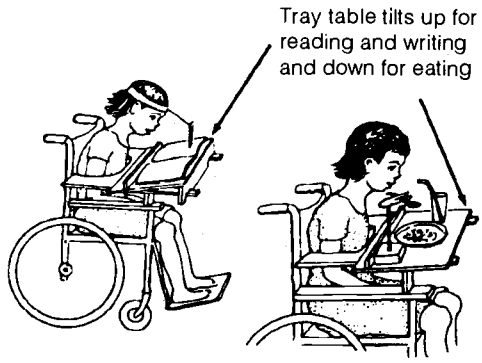
A thick handhold gives better grip and control.



For other ideas, see pages 264 and 402.

PAGE TURNER (Design for head)





Many children who have poor hand control and cannot write clearly by hand can learn to write well on a **typewriter** – using their hands or a stick attached to their heads. A typewriter may be a wise investment for an intelligent but severely disabled child – and may in time have provided a way for her to earn money.

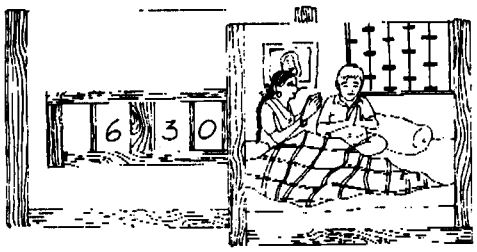


A **pocket calculator** is much cheaper than a typewriter. A disabled person who is good with numbers can do many different kinds of accounting jobs.

For more ideas on special aids and adaptations, see Chapter 27 on amputations, Chapter 9 on cerebral palsy, and Chapter 63 on special aids.

AIDS FOR TEACHING FOR CHILDREN WHOSE MINDS ARE SLOW TO DEVELOP.

Here are some very simple aids which can assist the child with mental retardation to learn better and easier. The general principal behind most of these aids is that they offer the child visual and sensory clues to learning a concept. There is no need to learn by rote. The immediate indication of correctness of his effort helps the child learn. The materials used for making these aids are easily available. All you need is some wood, cardboard, paper and pencils and somebody who can draw. These aids are being made and used at the Navjyoti Trust in Madras.

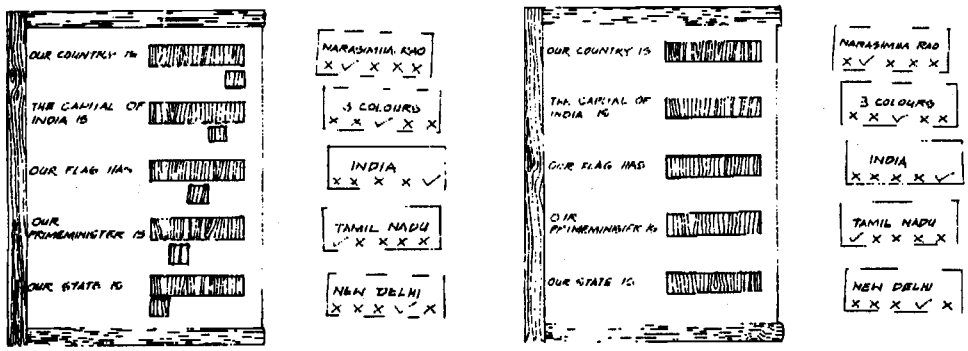


Navjyoti Trust

At 6.30 in the morning we get up and pray

The child learns to associate the picture on the card with a particular time of day. You can make different pictures of activities for different times of the day.

Special educators at the Navjyoti Trust found that it was easier for a child with mental retardation to follow digital display of time than an analogue display.



Navjyoti Trust

This simple teaching aid enables the student to fill in the blanks in simple sentences. The student places a caption card in the window next to the unfinished sentence. She then lifts the flap to see whether her answer is correct.

The flaps on the board are placed in such a way that the right (sign) will be indicated only if the correct caption card is inserted.

CHAPTER 55

Work

Possibilities and Training

For most people, some kind of work is necessary in order to eat and have a place to live In rural areas, the main work of many families involves farming, fishing, hunting and gathering, or other forms of food production. Equally important is the work of 'keeping house' and bringing up the family.

Who does most of the work within a family depends on local customs and the family's situation. In most poor families nearly everyone – women, men, and children–help with the work of survival. By the time they are 5 or 6 years old, children may be helping to take care of the babies, feed the chickens, herd the goats, shell and clean the grain, and to carry out other tasks so that the older members of the family are free to do other work. In many societies, children by age 8 or 10 bring in more income (food or money) than it costs their families to take care of them.

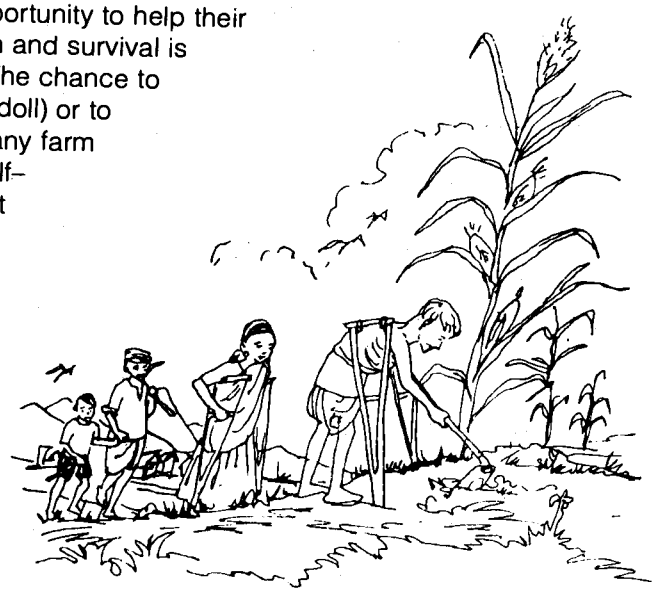
Work that frees people and work that makes them slaves



Work–whether it is done by adults or children – can be either a good or bad experience. It can help persons gain dignity and independence. Or it can take away their dignity, freedom, and health. How workers are affected depends on work conditions, on the fairness of wages, on workers rights, and on how much respect and equality exists between workers and bosses.

In some situations, especially in cities, many children are forced to work long, hard hours in unsafe or unhealthy work conditions for very low pay. Such 'child labor' is cruel, and may result in permanent damage to the child's body or spirit.

In some rural areas, children from the poorest families must also work long, hard hours under difficult conditions. But for many rural children, the opportunity to help their families with the labor of production and survival is a greater adventure than is 'play'. The chance to take care of a real baby (not just a doll) or to help grow the family food, gives many farm children a feeling of importance, self–confidence, and personal worth that is not often seen in city children.



As a child grows up, to be wanted and well cared for is not enough. **A young person needs to feel that he or she is needed.** To become 'independent' can be important. But just as important is **to develop an ability to do things for and with others, to contribute toward meeting the needs of family, friends, and community.**

Too often disabled children are not given the opportunity to become helpful or needed, or to learn the skills to contribute in an important way to the family or community. The family and community need to look ahead to the disabled child's future. They need to find ways to build on whatever strengths she has, so that she can have a full and meaningful role in the community.

A money–earning job is not the only meaningful role in society

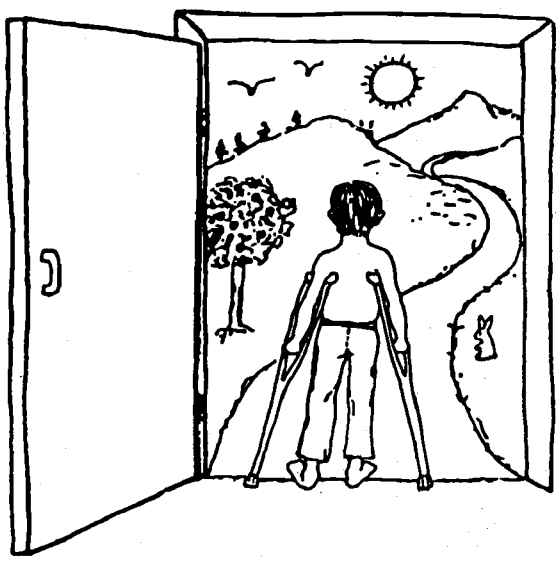
Although a money earning job is not the only meaningful role in society, every hand that brings a rupee into a poor family's purse, counts. More often than not economic factors make it necessary for disabled persons to work to earn money.

Most rehabilitation programs therefore try to train disabled persons in occupations where they can earn some money. This may be in a sheltered workshop or in self–employment efforts on a small scale.

A large number of families in the rural and urban slums areas follow traditional occupations. Wherever possible then, there is an attempt to integrate the disabled person in the work the family does. While here a person may not be directly earning money and becoming self sufficient, she is contributing significantly to the family income.

There are many ways, other than by working for money, that disabled persons can contribute to their family and community. They may be able to learn skills to help with daily activities in the home. Or they may become leaders for community action. As we discussed in Chapter 46, disabled villagers who are unable to do hard physical farm work, often make outstanding health workers (paid or volunteer), rehabilitation workers, popular organizers, or defenders of human rights.

The challenge, whenever possible, should be to build on the unique strengths, experience, and qualities of the disabled person. Help her to find a role in society that she can do better than most non–disabled persons. Disability does make a person different in certain ways, for better and for worse. Rather than pretending that the difference does not exist, it is wiser to accept the differences and look for ways that being disabled helps to deepen or strengthen the person. Help the person to have not just an ordinary role in society, but one that is in some ways outstanding. Persons like Helen Keller (a blind and deaf woman who become a social leader and agent for change) can be our role models.

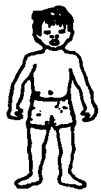


Our goal should always be to open doors for the child, not to close them.

ACCEPT THE CHILD'S WEAKNESSES AND DEVELOP HER STRENGTHS

Children with certain areas of weakness or disability often also have other areas of strength or ability. When deciding what work skills a child should be helped to develop, it is generally wise to pick those in areas where the child is strongest. For example:

A child who is mentally retarded but physically strong....



....may be happier and do better at learning certain physical skills



....than at spending a lot of time trying to learn mental skills



He will probably make a better farm worker than a writer or bookkeeper.

A child who is physically disabled but has a quick, intelligent mind....



....may be happier and do better learning mental skills....



....than trying to learn physical skills that will always be more difficult for her.



She may make a better health worker or school teacher than a farmer or grain grinder

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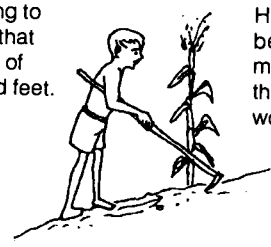
A child who has weak legs but strong arms and hands....



....may be happier and do better learning manual skills....



....than trying to learn skills that require use of his legs and feet.



He may make a better sandal maker or welder than a field worker.

A child who cannot see but has a good sense of hearing, touch, and rhythm....



....may be happier and do better learning skills that depend mainly on hearing and touch....



....than trying to learn jobs that are much more difficult without eyesight.



He will probably make a better village musician than a goat herder or hunter.

CAUTION: It usually makes sense to help a child develop specialized work skills in the areas where she is strongest. But it is also important for her to develop self-care and daily living skills as best as she can, even though this may be difficult. Thus the child who is mentally retarded needs to learn basic communication skills. The girl with ***spasticity*** needs to learn, if possible, how to prepare food and keep house. The weak legged boy or blind child needs to learn how to get from place to place.

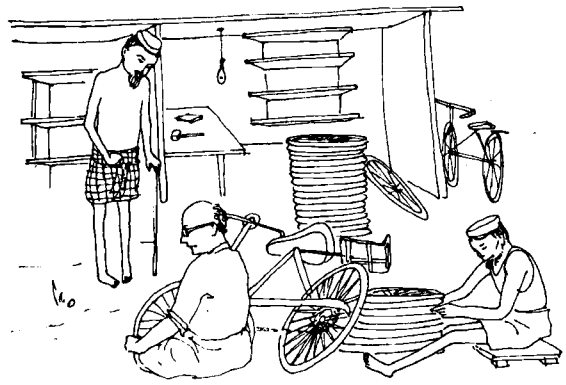
DIFFERENT WAYS TO WORK AND EARN

Self employment

Many disabled villagers will need to learn skills other than farm work. **If unemployment is high it may not be wise to train disabled persons for jobs where there is a lot of competition.** In fact any sort of paid job may be hard to get. Therefore, it often makes more sense **to teach young disabled persons skills so that they can become self-employed.** Or perhaps several disabled and non-disabled persons can become partners in a small home industry.

A rehabilitation center with a shop can teach young disabled persons different manual skills such as leatherwork, clothes making, wood-working or welding. While they are with the program, they can use these skills to make a wide range of rehabilitation and **orthopedic** equipment. They can also make toys, chairs, leather goods, clothes, and other objects for sale. The income from the sale of these things can help cover some of the costs of the rehabilitation program and training. When the learners have gained enough skills, perhaps the community program can help them set up their own small 'shop' in their home, village, or neighborhood.

Here is a true story of how after training a disabled person was able to encourage and give work to other disabled people in his village.



Anwar Pasha of village Bannur near Mysore, has Cerebral Palsy. All his limbs are affected and he finds it difficult to walk for long distances. However, he is able to do many things with his hands. His father ran a small cycle shop which was left unattended when he died suddenly. Being the eldest child Anwar Pasha had to look after his widowed mother and younger brother.

Anwar Pasha's life began to change when the District Rehabilitation Centre Team visited his village and promised to train him to look after his cycle shop. They also helped him get a loan of Rs.4000/- under the Integrated Rural Development Programme from the Karnataka Bank Ltd., Anwar Pasha bought five more cycles to sell in his shop. He also bought more material for repairing cycles.

This was not all. Anwar Pasha has now taken on two other apprentices, Khaleelulah and Mahalinga in his shop. Khaleelulah has Polio but he can walk and use his hands quite well. Mahalinga is partially sighted. His eyesight is deteriorating and may completely go one day but he has already started learning how to repair cycles under the able guidance of Anwar Pasha.

SELF-EMPLOYMENT — A WISE APPROACH WHERE JOBS ARE HARD TO GET



Nita sells vegetables in a small village in Midnapur district in Bengal. She got a small loan of Rs.500.00 from the bank in her village to buy the first lot of vegetables, a bucket and some baskets. She has her shop in her house. By evening nearly all of Nita's vegetables have been sold to the people in her neighborhood.

Self employment allows disabled people to work from the home or near the home. It is especially worthwhile for severely disabled people.

A small scale employment requires a very low capital investment.

The goods can be sold in the neighborhood itself.

There are several income generating programs of the government which disabled people can make use of. For example loans are given for small scale ventures under programs such at the IRDP (Integrated Rural Development Program), TRYSEM (Training Rural Youth for Self Employment) and others.

Nationalized banks also give loans for small scale businesses. Organizations such as the ***Khadi Village*** Industries Corporation also give loans for starting ventures that they are promoting.

In several countries, organizations for the disabled have started **revolving loan plans** that provide the disabled craftsperson with the basic equipment to start his or her own small business. The loans are paid back little by little over a reasonable time, so that the same money can be used to help another disabled person get started.

Here is another way in which an organization has helped disabled people to set up their own units. The Ramana Maharishi Academy for the Blind in Bangalore, trains young visually disabled people to make cartons for packaging consumer items. The trainees produce packing cases worth Rs.3 lakhs every month for major companies like Hindustan Lever, Liptons, Brooke – Bond, Ponds and Bangalore Pharmaceuticals. Each trainee is given a monthly stipend which is deposited in his name in the bank. At the end of the training period this money is used to help the young blind person set up his own unit.

Members of the Spastic Society of Northern India were even able to persuade government officials dealing with the TRYSEM project to include chalk making in its approved list of small businesses. The experience of Spastic Society showed that chalk making is particularly suitable as an occupation for a large number of people with cerebral palsy.

Working in the Family Trade

Although this is a book about solutions, there are some situations that arise out of our social system, for which there are no easy answers. These are situations we feel we must bring to the notice of our readers so that they may search for their own ways of tackling them.

One such situation is that of occupations that have for centuries been linked to different castes and creeds. For example in many villages trades like the blacksmith, carpenters, cobblers and potters are associated with different castes. If a disabled person's family works at a family trade the aim of most rehabilitation centres would be to train the disabled person in that trade. The advantage of this is that training can be given within the family and members of family can help the disabled person if need be.

But there are instances when this is not always possible. A disabled person may have to loose out on work because his caste does not permit it or because he does not belong to the caste which does the work he can be trained in. What then is the solution?

Ramu

Ramu's parents work as daily wage workers in silk looms owned by other rich people in a village near Bangalore. They work hard and for long hours and yet make just enough to eat and live. Ramu is mentally retarded but he can learn many things. When he came in contact with the local rehabilitation centre of *Sewa–in–Action*, the people at the centre taught Ramu to work in a silk reeling unit. The work was simple and with a lot of repetition and practice Ramu was able to work efficiently at the unit.

When they saw how well Ramu worked at the unit, his parents were encouraged to get a loan and buy a silk reeling unit.

Ramu now works at home and is slowly repaying the loan his parents took. Soon he will be able to buy more machines. And then may be his parents will never have to work as daily wage earners for other peoples.

Seeing Ramu's success many other people in his village have also got loans to buy silk reeling units and set up their own small scale units.

Kammalama

Kammalama lives in village T Narasipur near Mysore. She is moderately mentally retarded. Her parents are poor agricultural workers who did not have the time to teach her the skills of daily living. At 15 years of age Kammalama did not know how to dress herself, comb her hair or even have a bath. She would not speak and have very little interaction with anyone. She normally sat the whole day in a corner, rocking her body to an fro. When the District Rehabilitation Centre (DRC) from Mysore met Kammalama they felt that if they taught her a trade she may come out of her shell and take an interest in things around her.

And that is what happened. Kammalama was taught how to roll *aggarbatis* (incense sticks), along with some other trainees from different villages. To learn, she had to travel by bus from her village to the centre. Kammalama enjoyed here training so much that she learnt to get on to the right bus. She began to take care of her appearance and dressed better.

Although she did learn to roll Aggarbatis, she could not roll a large number. The DRC felt that she would need much more training. Then they thought, "Why not get Kammalama to work and train with Bassama who is also disabled." Bassama had trained earlier with the DRC team. Now she was making aggarbatis on her own and selling them. She got Rs.3–4 for a Kg of aggarbatis.

Bassama agreed. She could do with another hand to help her.

But as soon as the people in the village got to know of this plan they were up in arms. How could these two work together? Bassama was a high caste woman, while Kammalama belongs to a lower caste.

The village elders put their foot down. How could a woman of the lower caste work in the same place and in the same occupation as a woman of the upper caste.

Cooperative Ventures

A cooperative venture is another way for disabled people to earn and work. The Disabled cooperative movement started on a small scale in Bombay in the 1970's. It is now spreading all over Maharashtra and other states too. The cooperatives are being organized and run jointly by disabled and various voluntary and government agencies in the State. There are already over 60 such cooperatives with a membership of over 25,000 disabled people in Maharashtra.

Here is an example of how persons cured of leprosy have been able to train and earn well through a cooperative venture. As a result, they are now active and integrated members of society.

Even though people with leprosy were being cured at the Bandorwala Leprosy Hospital at Kondhawa, Pune, they could not get employment in the open market. The major reason for this being the social stigma attached to leprosy. Dr. Jal Mehta of the Pune District Leprosy Committee thought of a new and successful way to solve this problem.

The first step was to break the all powerful stigma.

Cured leprosy patients were trained alongwith people with other disabilities and also socially and economically disadvantaged able bodied people. They were trained to manufacture sophisticated industrial components which required mechanical and engineering skills.

The close contacts and interactions among the groups brought their families and communities closer together thus breaking the social isolation of people cured of leprosy. But even after this training it was difficult for these people to find jobs in the open market.

A solution had to be found.

The answer came in the formation of the **Dr.Minoo Mehta Industrial Production Cooperative Society for the Welfare of the Handicapped Limited.**

This cooperative society is controlled by people who have been cured of leprosy. The society provides training free of cost to people referred by the Pune District Leprosy Committee. Each member of the society earns about Rs.2,000/- a month. The society also contributes to the welfare and rehabilitation of people affected with leprosy. A sizable amount of its earnings are set aside for this purpose.

The success of the society also lies in the fact that many of its members have inter married and set up homes within the community. They now live as respected members of the community.

(Adapted from The Mehta Cooperative Rehabilitation Model Indlan Journal of Disability and Rehabilitation Vol.5 issue-I Jan-June 91.)

"Sheltered workshops"– yes or no ?

Sheltered workshops are special training and production centers for disabled persons. The idea is to provide a work opportunity and a little pay to those who would find it difficult to get training and employment 'on the outside'.

At best, these workshops can be a very valuable experience for participants, and may serve as a step toward greater independence. They help participants gain the technical and social skills, work habits, responsibility, and self–confidence needed for outside employment or self employment.

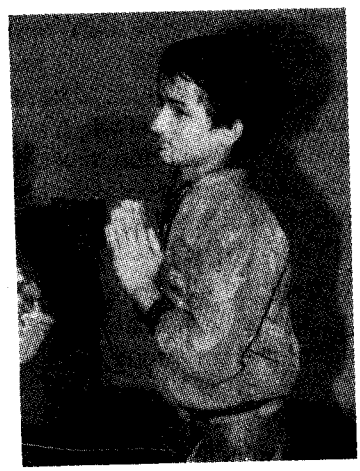
At worst, sheltered workshops can (and often do) actually hold back the development and crush the spirit of participants. Too often they are run by persons who treat the workers like babies or slaves, giving them simple, repetitive tasks. The workers are not involved in the planning, organization, or running of the program. They are simply told what to do. They become increasingly dependent on the center and fearful of their inability to make it on their own in the outside world.

Perhaps the key difference between these two kinds of sheltered workshops is the question of **control and quality**. If the participants are involved in the direction and decision making of their own program, then they will grow and mature along with the program. Perhaps they will make more 'mistakes' than a program that is controlled and run by 'superiors'. But they will learn from more mistakes. At the same time they learn crafts, they learn skills in decision making, problem solving and small group democracy–essential skills for improving life in the 'real world'.

A community – based rehabilitation program run by disabled persons may have some features of a sheltered workshop. It may provide special training and work opportunities adjusted to the pace, abilities and limitations of each participant. It may provide such an enjoyable 'home' and 'family' setting that some persons may choose to keep working rather than to "move on' into the 'outside world'. But because it is a program run by disabled persons, and major decisions are made at all – group meetings, it tends to be a dignifying and liberating experience.

A program where disabled and non – disabled persons work side by side, sharing equally in decisions and responsibility, may be even more liberating.

Here is the true story of Lal Singh, a teenager with Hydrocephaly (See chapter 32) who has benefited from the sheltered workshop run by SAMADHAN (see chapter 56) in the low income resettlement colony of Dakshinpuri in Delhi. He has learned to cut wooden blocks on the machine, sand paper and then paint them under the supervision and training of a carpenter. After 5 years of training he is now receiving a salary which has earned him the respect of his family as well as the community.



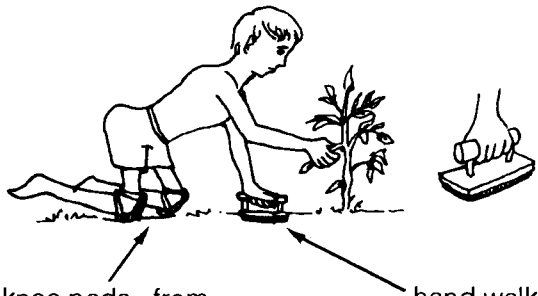
(Photo : SAMADHAN, Delhi)

Adaptations for farm work and Gardening

Persons with weakness in their lower bodies but who have strong arms and hands can learn a wide variety of work skills where they can sit and use their hands (See list of skills on p. 620). However, for many villagers, the growing of food is central to their lives.

If certain **adaptations** are made, disabled villagers can often help with farming and gardening. Here are a few suggestions.

AIDS FOR CRAWLING

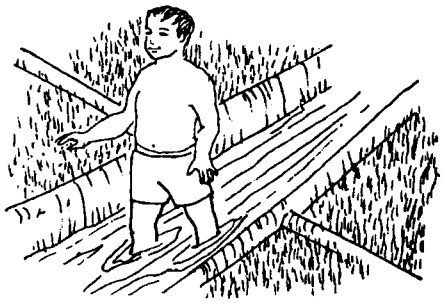


knee pads– from pieces of old rubber tyre padded inside

hand walker

hand walker attached to garden trowel

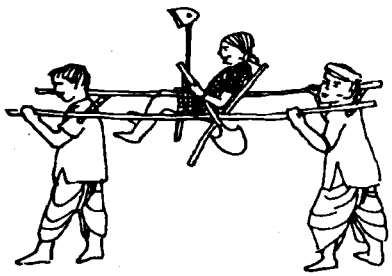


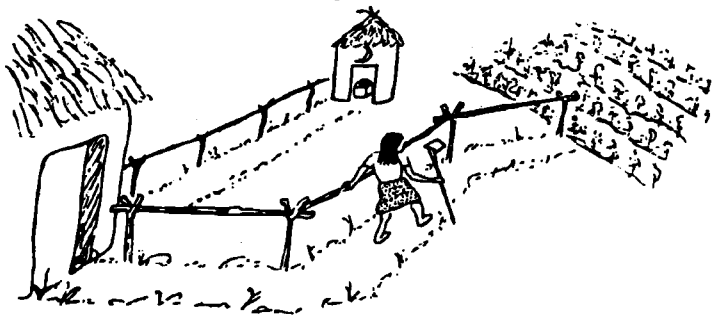


These streams of water that go around each plot of land mark the boundaries of the farm. A farmer who is blind finds it easier to mover from plot to plot by wading in the water. The running water of the stream carries away any thorns or sharp objects. The stream serves as an obstacle free path.

OFF – ROAD TRANSPORT

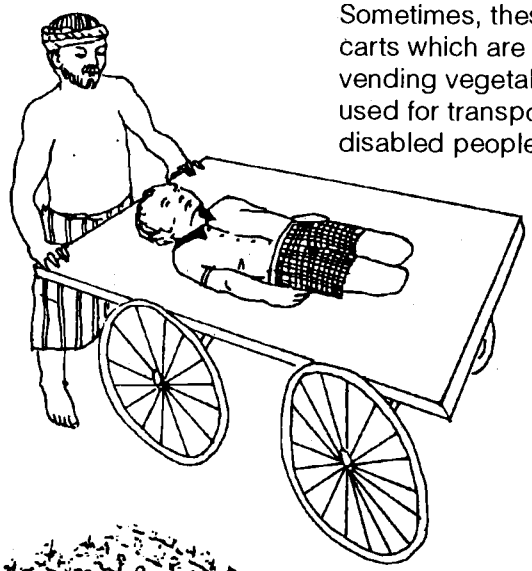
Getting to distant fields over rough trails may be difficult for the young person who cannot walk. A simple carrying frame can be used to carry the child and also the tools and grain.





ON–ROAD TRANSPORT

Sometimes, these push carts which are used for vending vegetables, are used for transporting the disabled people.



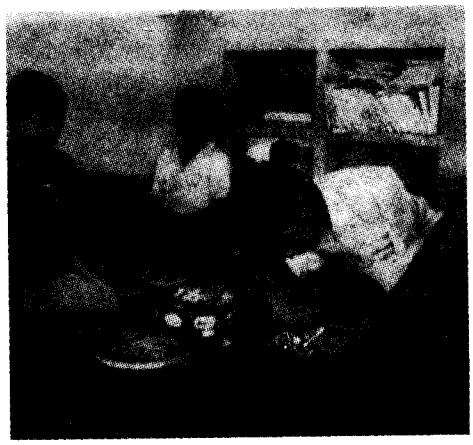
GUIDELINES OR RAILS

For the child who is blind, or has difficulty with balance, hand rails may make it easier to get from the house to the garden, the latrine, and the well or water hole.

LEARNING SKILLS FOR AN ACTIVE OR PRODUCTIVE ROLE IN THE COMMUNITY

Development of the mind

Learning skills that require more mental than physical activity can help the physically disabled child to gain a place in the community.



In Melkate, India, The Janapada Seva Trust teaches disabled village children many productive skills. Here, a boy without hands uses his foot to draw greeting cards, which are later sold.

For development of skills such as reading, writing, and arithmetic, **when possible, it is usually best that the disabled child go to school.** Ideas for helping the child get to school and be accepted there are discussed in chapters 48 and 54. **If the child cannot go to school, figure out ways for her to be taught at home** – perhaps by school children.

As soon as the child learns to read and write, try to buy or borrow simple, interesting, and educational books. With these the child can develop her mind further.

Starting a library in the village or urban slums is often an excellent idea. In fact, a disabled young person may be able to become the 'librarian' — and a non – formal educator.

To open up other possibilities, help your community recognize both the needs and value of disabled and other disadvantaged persons (such as single mothers). **When deciding who to choose for public service jobs and community responsibilities, try to make it a community policy to consider choosing persons who have disabilities or special needs.**

Although they are sometimes unable to do hard physical farm work, disabled persons can often make outstanding health workers, cooperative administrators, shopkeepers, librarians, cultural promoters, or child care center coordinators– if they are given the chance.



In a village, a young person who learns to read and write can become a 'librarian' and sharer of information.

TRAINING

The Integrated Approach

When possible, it is usually best that skills training for disabled persons take place together with skills training for non–disabled persons. For example:

- A disabled girl can go to the river to learn to wash clothes with other girls and their mothers.
- A disabled boy can go to the fields to help plant, weed, and harvest alongside his able–bodied brothers, sisters, and father.
- A disabled child can go to the same school as other children, and then go on to some specialized training course.
- A disabled young man or woman may enter a shop or production team as an apprentice just as non–disabled young persons often do.

For a ***mildly or moderately disabled*** child, there are many possibilities to prepare for life's work together with non–disabled children–especially if parents encourage the child and explore opportunities. A community rehabilitation program can help by encouraging schoolteachers, schoolchildren, training program instructors, craftspersons, and possible employers to be more open to giving disabled young people an equal chance.

For more severely disabled young people, opportunities for integrated education or skills training will be much more limited. Alternatives need to be looked for, or arranged, especially in communities that are still not open to giving them an equal chance.

Special training possibilities

Different approaches have been tried to help disabled persons learn specific skills. In cities, special training centres are sometimes set up for children with similar disabilities. These include programs for deaf children, centers for retarded young persons, and programs for blind children. Each program chooses skills and activities suited to the particular limitations and abilities of the group. For example, a skills training and production program for the blind may focus on skills that depend largely on touch, such as weaving or chalk making.

In smaller villages, it is often not possible to bring together enough persons with the same kind of disability to create a specialized training program just for them.

However, a community rehabilitation program, can, in its workshop, include a variety of skills training opportunities which can be adapted to persons with a wide range of disabilities.

Vocational Rehabilitation Centres. (VRCs)

The Govt. of India has set up 17 VRCs in different states and Unior Territories for persons with Visual, Speech & Hearing, Orthopedic and Mental (51–70 IQ levels) handicap. After a medical evaluation an eligible candidate is provided with an initial training of one month's duration in one of the following five vocations for which he is found suitable:

- Radio technology
- Carpentry
- Tailoring
- Stenography
- Metal fitter/welding

Thereafter the candidate is given intensive training for one year. The VRCs also help in getting admissions into technical and other institutes for further training/education. On completion of training assistance is rendered in securing employment either in the public or private sectors. Help is also provided for allotment of self employment facilities such as gas agencies, telephone booths, ration/ kerosene shops, petrol pumps etc. Where needed, the VRCs also help the individuals in getting travel and other concessions provided by the Govt., procuring Bank loans, Govt. grants, aids & appliances etc.

A countrywide list of VRCs is on page at the end of book.

Disabled villagers can become skilled in a wide variety of manual skills. Here we list some skills that are taught in different rehabilitation programs, training programs, and special workshops.

* skills marked with a star are sometimes taught to blind persons
☐ skills marked with a box are sometimes taught to mentally retarded persons.

leatherwork ☐
sandal and shoe making and repair
metal work of a wide variety
welding
radio and television repair
electrical and mechanical repairs
weaving of cloth, blankets etc. *
sewing of clothes making ☐
toy making *
basket weaving * ☐
doll making ☐
carpentry * ☐
cabinet and furniture making *
hospital equipment making
making rehabilitation equipment and aids
wheelchair making
prosthetic limb making
drawing, painting, sculpture and design, wood or ivory carving
production of simple marketplace gadgets, cages, utensils and knickknacks.
designing and making greeting cards
printing and silk-screening
pottery making *
broom making * ☐
chalk making * ☐
candle making *
artificial flower making ☐
typing and secretarial skills
bookkeeping, accounting
bee keeping
knife, scissor and saw sharpening ☐
gardening and vegetable raising * ☐
animal raising chickens, ducks, goats, rabbits, pigs, fish) * ☐
managing a small store or street shop *
cooking and restaurant management
health work
jewelry making
rope and string making * ☐
landscaping, grounds maintenance ☐
janitorial service (cleaning and maintenance) ☐
fish net making and repair *
teaching *
playing music *
laundry work, pressing
hair cutting, dressing
dental work

The above list includes only a few of the activities that disabled persons have learned in order to run their own small business or set up shop in their home. As much as is possible, let the disabled person decide what skill or skills she wants to learn. Choices that are possible will depend on the person's combination of disability, abilities and interest as well as on the local situation, resources, market, training opportunities, and other local factors.

Combining work with therapy

Whenever possible, look for work that will help a disabled person fit into the life of his or her community, and that will also provide needed exercise or therapy. Here is one example from the Sarvodaya community – based rehabilitation program in Beruwala., Sri Lanka.

With the help of her family and a village rehabilitation volunteer, this girl with cerebral palsy learned to make rope from coconut fiber (jute). This is a common village craft, so she can work with other villagers.



Separating and preparing the fibers is good therapy for her spastic hands.



Twisting the fiber with this wheel to make more rope helps her move her stiff arms in a smooth circle–providing excellent, active therapy while she works.

NOTES:

CHAPTER 56

Examples of Community – Directed Programs

In this chapter we give examples of ***rehabilitation*** programs in 4 countries (Mexico, Pakistan, Bangladesh and India. The examples from India have been selected from different parts of the country). We do not claim that the examples given here are the most outstanding or successful programs.

Some of the programs described here are working in urban areas as while others have outreach programs in villages. Some are run by disabled people themselves. They all work closely with the community using its local resources also to provide services to disabled children and their families.

Our description of each program must be brief. We will, therefore, try to focus on their most interesting and original feature, especially those that could serve as examples for other programs.

1. PROJIMO–RURAL MEXICO

Project PROJIMO is a rural rehabilitation program in western Mexico, run by disabled villagers, to serve disabled children and their families. It was started in 1982 by disabled village health workers from an older community–based health program (Project Piaxtla)

PROJIMO's goal is to help disabled children and their families become more self–reliant. It aims to provide low–cost, high–quality services to poor families who cannot obtain or afford services elsewhere.

The PROJIMO team provides a wide range of rehabilitation activities and equipment. These include: family counseling and training, *therapy*, work and skills training, brace making, artificial limbs, wheelchair making, special seating and therapeutic aids.

PROJIMO is based in one small village but serves children and their families from neighboring towns and villages, and even from the closest cities (over 100 miles away). Local villagers cooperate by taking visiting disabled children and their families into the homes. Schoolchildren help make the playground–for–all–children and toys for disabled children.



Part of the PROJIMO team

PROJIMO DIFFERS FROM MANY REHABILITATION PROGRAMS IN A NUMBER OF WAYS:

1. **Community control.** Unlike many community-based programs, which are designed and run by outsiders, PROJIMO is run and controlled by local disabled villagers.

2. **De-professionalization.** The village team, although they have mastered many 'professional' skills is made up of disabled persons with an average education of only 3 years of primary school. Their training has been mostly of the non formal, learn by doing type. There are no titled professionals on the PROJIMO staff. However, therapists, brace makers, limb makers, and other rehabilitation professionals are invited for short visits to teach rather than to practice their skills.

> The PROJIMO team believes that only by simplifying rehabilitation knowledge and skills to make them widely available in the community can the millions of unserved disabled children in the world receive the basic assistance they need.



Roberto Fajardo and Mari Picos, two of the leaders of PROJIMO,evaluate a child's developmental level Both Roberto and Mari first came for rehabilitation, then stayed in order to help others.

3. **Equality between service providers and receivers.** When asked how many workers they have the PROJIMO team has no easy answer. This is because there is no clear line between those who provide services and those who receive them. Visiting disabled young persons and their families are invited help in whatever way they can Most of the PROJIMO workers first came for rehabilitation themselves. They began to help in different ways, decided to stay and gradually became team members.

4. **Self-government through group process.** The PROJIMO team has been trying to develop an approach to planning, organization and decision-making in which all participants take part. They are trying to free themselves from the typical boss-servant work relationship and form more of a work partnership. The group elects its coordinators on a one-month rotating basis so that everyone has a turn. This leads to a lot of inefficiency and confusion but to a much more democratic group process. (See p. 576).



Most of the training of the PROJIMO team members is through guided 'learning by doing'. Here, PROJIMO workers practice exercises under the guidance of a visiting *physiotherapist.* Parents, children, and anyone who wants to learn are welcome.

5. **Modest earnings.** The PROJIMO team believes that they should work for the same low pay as that of the farming and laboring families they serve. They can see that the high pay demanded by professionals and technicians is one reason that the children of the poor often cannot get the therapy and aids they need.

6. **Unity with all who are marginalized.** The PROJIMO team sees society's unfair attitudes toward the disabled as only one aspect of an unjust social structure. They feel that disabled persons should join in solidarity with all who are rejected. misjudged exploited, or not treated as equals. This feeling has led the team to become more self-critical and to seek greater equality for women within their own group.

Thus the PROJIMO team views its role not only as one of helping disabled children and their families gain power, but as part of the larger struggle for social change and liberation of all who are on the bottom.

7. **Grassroots multiplying effect.** The PROJIMO approach has been spreading in various ways. Locally, families of disabled children in a number of towns and villages have begun to organize, build playgrounds, and form their own special education programs as more or less 'satellites' of PROJIMO. PROJIMO has also invited visitors from rehabilitation and community health programs in the parts of Mexico and Latin America to visit and take ideas back with them. Some programs have sent disabled representatives to work and learn at PROJIMO for several months so they can start similar programs in their own area.



The PROJIMO experience has been the basis for writing this book. Different examples or descriptions from PROJIMO are discussed in various chapters. For further references, see the Index A64-page report on PROJIMO with many illustrations is available from The Hesperian Foundation (see p. 769)

2. COMMUNITY-DIRECTED REHABILITATION DEVELOPMENT-PAKISTAN

The program began in Peshawar in the Northwest Frontier Province of Pakistan as a small play group for 8 ***mentally*** handicapped children. In 1978 the 3 Pakistani staff were joined by a Welsh special education teacher and her husband. During the next 7 years the play group grew to become a community rehabilitation and resource center with daily participation of 70 physically and 40 mentally and multiply disabled children.



Splinting a leg straighten a knee *Contracture*

Local staff persons are trained by the few professionals in special education, physical therapy, brace making, parent counseling, and planning services.

An important part of the program is the **Community Rehabilitation Development** Project. The big, largely rural area surrounding Peshawar is very underserved. To accomplish as much as possible with limited resources, disabled children in towns were considered first. Volunteer college students went door–to–door to find and bring together parents and relatives of disabled children. Public meetings were held and an Association was formed in each town with the aim of starting rehabilitation activities. People (sometimes young disabled persons) were chosen and sent to learn basic skills at the Peshawar center, Meanwhile, the Association committee raised funds and found a place that could serve as a modest rehabilitation center.

Although the parent program has had UNICEF and other outside funding, the neighborhood rehabilitation centers have mostly been funded locally, some with a government subsidy. Management is entirely in the hands of local people.

In addition to providing daily special education and physical therapy, the neighborhood centers act as a resource within their districts. They distribute advice, pamphlets, and books to families for home rehabilitation. Where possible, going to normal schools is encouraged.

12–minute radio broadcasts about home rehabilitation started in 1984. (The scripts for these, which are excellent, are available.) Also, the program is looking into appropriate handicrafts by which disabled young people can contribute to their family's income. A manual of these handicrafts is in preparation.



Helping a child begin to learn to move

Also available is an excellent book by Christine Miles, called ***Special Education for Mentally Handicapped Pupils: A Teaching Manual.*** It points out the importance of re–thinking special education to meet local needs and customs in developing countries. (See the reference section, p. 772)

Mike Miles, Christine's husband, has also written many excellent and critical papers on rehabilitation efforts–and problems–in developing countries (see p. 773).

The Peshawar program has succeeded in promoting community–directed rehabilitation activities in much of th Northwest Frontier through organizing and already motivated group (parents of disabled children). One of their keys to success is to "Do the easy thing first!"

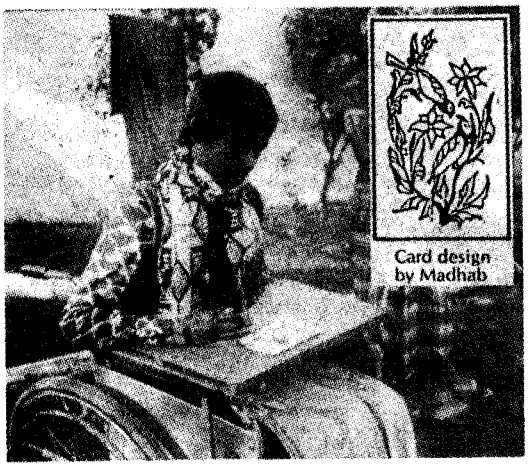


Going for a ride.

3. CENTRE FOR THE REHABILITATION OF THE PARALYZED (CRP) – BANGLADESH

Located in the capital Dhaka, CRP is run by a local team, with the help of a British physiotherapist. Four of the staff members have spinal injuries themselves.

The CRP provides short–and long–term PARTICIPATORY rehabilitation to severely ***paralyzed*** persons. Almost from the day of arrival, newly paralyzed persons begin to do jobs to help the Centre bring in some income. Those who must lie on stretcher trolleys (wheel cots) work on jobs ranging from making paper bags to be sold in the local marketplace, to welding and painting of orthopedic equipment. The group produces orthopedic and hospital equipment, not only for those it serves directly, but also for sale in hospitals and in the community.



Madhab, who is quadriplegic and who has been employed as the Center's counselor since 1980, paints by means of a simple hand splint. Disabled workers print his paintings as greeting cards and sell them to bring in money. Madhab is responsible for the education program. He supervises those who read and write, who teach classes to those who do not.

CRP teaches practical skills through 'learning by doing'. The work that participants do not only brings in money for the program, but also teaches them ways to earn money after they return home. Skills learned are mostly those that will let persons have their own small home business–a roadside stand, sewing and tailoring, weaving, welding, and metalwork.

CRP has developed a wide range of low–cost ***orthopedic*** and rehabilitation equipment adapted to the needs and lifestyle of local villagers. Examples are ground level wheelchairs, or trolleys, for those who cook and eat on the floor (see p. for 716) and simple metal frame beds that can be easily lowered to near ground level for easy transfer into the low trolleys (see p. 696).

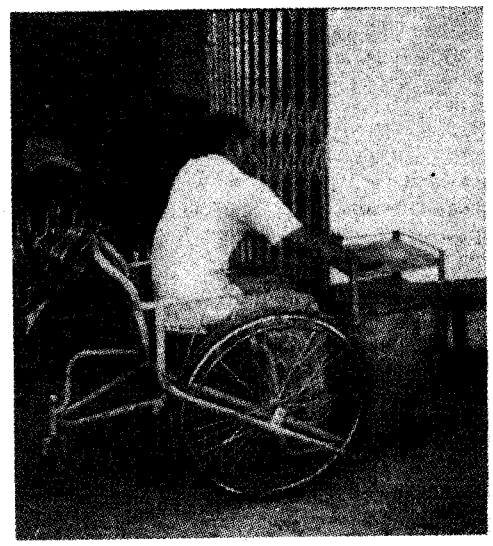


Badd, who is quadriplegic, pedals a CRP–made 'exercycle' while Delawar, paralyzed by tuberculosis of the spine, practices walking.

Although CRP is much loved by disabled persons and their families, it has suffered attacks–sometimes physical–from opposition groups. (Many successful community–directed programs have faced similar difficulties–partly because they provide friendly, flexible, effective care that differs so much from the services provided by many large institutions.)

The Centre for the Rehabilitation of the Paralyzed is financed mainly from outside grants and partly from the sale of its products.

For more information on this center and its equipment. see p. 233, 584, and 620.



A worker in the CRP – made wheelchair makes a bedside stand to be sold to a local hospital.

4. SHREE RAMANA MAHARISHI ACADEMY FOR THE BLIND – BANGALORE

The Shree Ramana Maharishi Academy for the Blind at Bangalore (SRMAB) was started on 18th June 1969, with a group of young and dedicated volunteers.

The basic aim of the academy is to rehabilitate visually impaired persons from rural and semi-urban areas by providing education, work training and placement.

Over 300 students from poor areas of Karnataka, Andhra Pradesh and Tamil Nadu study at the residential school of the academy. Apart from the regular curriculum the school provides specialized training for visually impaired children and adults in orientation and mobility, typing and extra curricular activities like gardening. This is the only academy in India that trains visually handicapped people in classical dance. At the academy itself, students master important trades like dairy farming, sericulture and agriculture. Many students come from rural areas to attend this course and then go back to their own villages to set up independent and successful units.

As a result they are able to go back to integrate as useful and respected members of their own communities. While learning, they also produce crops for sale and food for the center's kitchen which is cooked using gas from a tank fed with dung from the cowshed (a Gobar Gas Plant).

The rural outreach of Ramana Maharishi is now being expanded to reach all categories of disabled people in the rural areas.

Children above the age of fourteen also get trained for job opportunities such as packaging and learning to operate heavy industrial machinery at the academy. The packages they make as apprentices are of the highest quality and compete in the open market for orders. They are commissioned by big companies. (see p. 613)

A major project of the academy is its rural outreach project The Thirumurthy Rural Development Centre situated 40 kilometers outside Bangalore city. This is where visually disabled persons come to learn and practice vocations such as sericulture, fisheries, agriculture, horticulture, poultry farming. The training has also a strong theoretical component that equips them with an additional knowledge of the field they are going to be working in.



5. SEWA–IN–ACTION – BANGALORE, A RURAL OUTREACH PROGRAM WITH PARENT PARTICIPATION

SEWA–IN–ACTION has been functioning since 1985 in the Bangalore and Kolar districts of Karnataka.

The organisation has been set up with the belief that all people with disabilities – whatever may be its severity, – should be able to live as valued members of our community. This means reversing long standing prejudices and disadvantages, that people with disabilities have had to live with.

The main objective of SEWA IN ACTION is to develop culturally appropriate and cost effective services for disabled people. This is done with the collaboration for disabled people, their families and a wide range of grassroot level rehabilitation practitioners. These practioners are often men and women who are active in the affairs of their own communities. Their enthusiasm is constantly supplemented with the knowledge of teams of workers, skilled in dealing with different types of disabilities. In fact SEWA–IN–ACTION uses its own resources for training people to deal with many disabilities at the community level.

The formation of Self Help Groups and the provision of home based services are two important features of the project. The self help groups are usually formed by groups of parents of disabled children. They function as a nodal point to provide a range of services to their own and other disabled children in the village. They provide a forum for parents to discuss their problems, share their experiences, and find other parents who are willing to share in the care of severely disabled children.

The success of the self help groups lies in the fact that parents who were earlier hesitant to even acknowledge in public that they had a disabled child, are now bringing their children to the group.

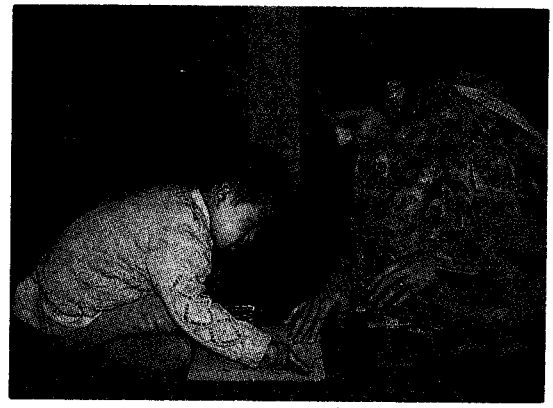
Related to these are the Mathrumandalis. A Mathuru mandali consists of the mothers of disabled and normal children in the local area. These mothers get together to discuss with a teacher, problems related to hygiene, environment, health and disability. They are then able to look after their own disabled children as well as advise other parents of disabled children. Home based services are provided to severely disabled children, who are unable to come to a self help group. Once the child is assessed an individual educational programme with long term and short term activities is drawn up. The grassroot worker visits the home of the child once a week. Here it is the parents of the young children who are helped to carry out the activities and in methods of early stimulation. Home based training demistifies the rehabilitation process and empowers the parent to take decisions and monitor the progress of their child.

In the difficult area of work training SEWA IN ACTION attempts to integrate disabled children into their family trades. The advantage of this is that the child can do jobs that the whole family is involved in and is thus easily integrated and accepted by others. The training once again can be given by the family itself, with some help from a trained.

There have been instances where the disabled children have become the major contributors to the family income.

6. SAMADHAN, NEW DELHI :
Services for people with mental handicap in urban low income areas.

Samadhan which means SOLUTION to problems, was initiated to fill the gap in the delivery of services to people with mental handicap and to their families. Samadhan started its work in 1981, with special focus in the low income areas of Delhi.

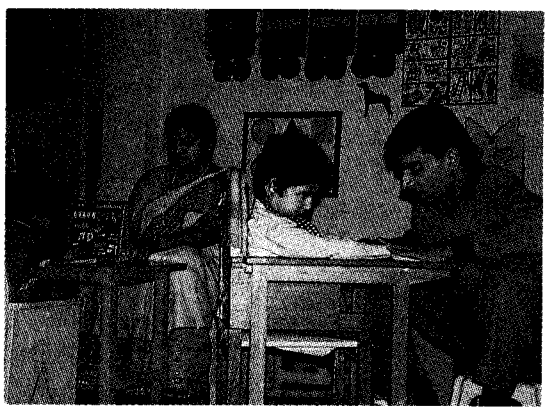


Home Intervention Program

Beginning with a campaign on Awareness of mental handicap, services today include a range of facilities. The day care centres established in the resettlement colonies are the focal point for community outreach programs and function as a support base. Initially SAMADHAN's program began working with fully trained professional special education teachers but for a variety of reasons this did not work. When the teachers resisted visiting children in their homes, lay women from the local community were selected and trained to replace them. In many ways this showed that local lay workers are often able to meet the needs of disabled children better than highly trained professional from the outside.

Supportive services include:

- Parent counselling and guidance.
- Training of the caregiver in the management of the disabled child in the home.
- Training motivated community members to take on the responsibility of providing for their disabled people.
- Providing opportunities to mentally handicapped people for expressing their creative talents through use of art as therapy.
- Referrals to other agencies dealing with disablities other than mental retardation.
- Training professional groups such as Dais (traditional birth attendents) teachers etc., in the indentification and care of mentally retarded children.
- Screening, assessment and diagnosis by a multi-disciplinary team through a rehabilitation.



A special Education session in progress.

The aim of these services is to give the family and the community a sense of confidence in there own abilities. The fact that even minimally trained or educated people in the community can function effectively as teachers of disabled people is a positive example which encourages community participation. Many other organisations working in the same areas have taken on some of the responsibilities and have contributed to the continuation of services started. Samadhan ensures that professional help is at hand and involves those members of the community who can take on the responsibility.

Early Intervention

An early intervention program caters to infants and children in the 0–5 age group. The intervention is given by trained and committed workers from the community. The skills of home management is transferred to the mother (or care giver) in a home based program. The assessment and other necessary services are provided by a centre based rehabilitation clinic.

Rehabilitation Clinic

The centre based program has evolved into a clinical model where parents come to attend the once a week Rehabilitation Clinic that functions in each of Samadhan's target areas. Supportive services such as parent counselling, staff training, therapy, assessment and diagnosis is provided by a team of specialists. Linking of a trained community worker called a Home Advisor to a specific family for home intervention, referrals to services not provided by Samadhan, such as those for children who have visual or hearing disability as well as referrals for surgery to hospitals when necessary is also done at the clinic.

An advantage of this clinic is the continuous follow up and monitoring by the home advisor and clinic team and the possibility of the child's eventual admission into the special education and later the vocational training units run by Samadhan.

Awareness Programs

To strengthen this work, awareness programs using street theatre, puppet theatre (Jan Madhyam organises the puppet shows, see chapter on Popular Theatre), films, slide shows and talks by doctors are conducted in each of the three target areas. In addition intensive discussions with community leaders helps identify the needs of the community in relation to their disabled people and also to provide information to take positive and corrective steps towards their rehabilitation.

Special Education

A day care centre offers special education. With a teacher ratio of 1:5, children receive special education from teachers aids (all of them are selected from the community) trained by Samadhan in a 4 month training program and continuous 'hands–on' training thereafter. A special educator monitors the work. The children in the age group of 5–14 are trained in self help skills.

Vocational Training

Vocational Training given in skills required vocational training is by the trades practised in the community. Each centres offers different programs such as woodwork, tailoring and farming.

The aim of these sevices is to give the family and the community a sense of confidence in there own abilities. The fact that even minimally trained or educated people in the community can function effectively as teachers of disabled people is a positive example which encourages community participation. Many other organisations working in the same areas have taken on some of the responsibilities and have contributed to the continution of services started. Samadhan ensures that professional help is at hand and involves those members of the community who can take on the responsibility and work in partnership for the benefit of the disabled in the community. One such example is the parent self–help group which is concerned and controlled wholly by parents.



A group counselling session.

Therapy through the arts

Children are encouraged to use music, dance and drama to express themselves in their own way. Role playing helps in overcoming frustrations and dramatic play is an excellent medium for improving social, language and communication skills.

A program of recreational activities called ARTS (Art, Recreation, Theatre and Song) offers mentally handicapped people of all age groups a platform for learning through the ARTS in a once a week program.

Long distance intervention program

Apart from providing services in these poor communities, Samadhan also offers day care facilities in a centre based intensive early intervention program to children of all socio–economic classes from different parts of the city. This program prepares children for admission into other special schools.



A speech therapist working with a child in the Early Intervention Program.

Early intervention to outstation children is provided by this centre. Individual programs are planned after an initial assessment. A program sheet for a fixed period of time outlining the different skills to be taught is given to the parents. They are expected to follow accordingly. Constant interaction between the parents and the centre helps clarify doubts, provides and opportunity for counselling etc.

7. BARODA CITIZENS COUNCIL, An Urban Community Development Project

The Baroda Citizens' Council (BCC) was established in 1964, and has been working as a voluntary agency in promoting urban community development and rehabilitation of disabled children in the slums of Baroda city.

The BCC aims at providing total rehabilitation and promoting self reliance in disabled people. This means, giving comprehensive services, including early detection, intervention, and the prevention of disabilities. It works towards ensuring the education of disabled children, the training of disabled people and their involvement in the economic programmes of the country.

During the year 1983–88 the B C C launched a special programme on the 'Prevention, Early Detection and Intervention of childhood disabilities in the slums of Baroda.

The uniqueness of the programme lay in the fact that BCC was able to involve community leaders and volunteers in the community; parents and teachers at the schools and Balwadis, in the whole programme. They began by conducting a door to door survey to identify all the disabled children below 15 years of age in the 325 slums of Baroda city. Special emphasis was laid on identifying disabled children between the 0–3 age group. In all, one thousand and seven hundred (1700) children were identified.

A research based profile of the identified children and the communities they live in, threw up some significant pointers. It was found that the majority of the children who were identified as disabled were only partially immunized. Over 60% of the children were suffering from polio.

Most of the identified children belonged to families with a monthly income of less than Rs. 500. Fathers and mothers were mainly employed in the unorganized sector where there are no medical benefits. Most of the parents were not educated and belonged to the socially weaker sections of society.

All these factros combined together to make the rehabilitation of the disabled child even more difficult.

Apart from a comprehensive programme of medical and educational interventions, the Baroda Citizens' Council decided to tackle the problem at its root. A massive immunisation programme was launched where all children from the ages of 0–6 were immunized against all the vaccine preventible diseases.

Volunteers went from door to door vaccinating the children. Here again the BCC gathered the support of hospitals, the Civil authorities and other concerned non–governmental organisations in the city. Even more crucial was the support of the leaders of the community.

In the area of detection and early intervention the BCC laid special emphasis on detecting hidden disabilities amongst children in the 0–3 age group. Sometimes the child's physical and mental development is delayed and this may eventually result in a disability. But in this age group the disability is always not obviously visible. Therefore, early detection of such delayed development helps in either preventing potential disability or in faster rehabilitation. An intensive house to house survey of all the slums of Baroda revealed that over 50% or more of the developmentally delayed children were disabled due to lack of nutrition. They were, protein calorie malnourished children who were often sick.

These children urgently needed nutritional supplements rather than any other kind of rehabilitation. And this is what the BCC was able to provide them.

One of the major strengths of BCC is that it is involved in a lot of action research programmes on the problems of Baroda city.

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8. REHABILITATION CENTRES FOR CHILDREN (RCFC) – CALCUTTA

Rehabilitation Centres for Children was started in 1973 to offer facilities for treatment and rehabilitation to physically handicapped (orthopedically) children from poor homes living in West Bengal and the eastern parts of India. Today RCFC provides physiotherapy, hydrotherapy, nutrition, corrective surgery and mobility aids to children who come here from places as far off as Manipur, Sikkim and even Bangladesh.

A 17 bed Hospital

RCFC has a full fledged hospital which undertakes corrective surgery for bone deformities, muscle transfers to strengthen weak tissues etc.

A workshop for making aids and appliances

This workshop makes low cost aids using locally available materials and skills. The aids are made after considerable research depending on the needs of rural children. Aids such as braces, supports, artificial limbs etc. are provided.

Children's Development department.

RCFC runs classes for children up to the 4th standard.and also tries to give extra coaching to older children. A variety of different crafts are taught to help them express their creative abilities.

From a centre based program it has now evolved into a community based rehabilitation program offering a wide range of services, from immunization, care of pregnant mother to early detection of disability and regular clinic held at the RCFC to cater to the needs.

9. SAMAJ KALYAN KENDRA – JAMMU

PREVENTION, DETECTION AND REHABILITATION OF DISABLED IN THE COMMUNITY – BISHNAH BLOCK.

Samaj Kalyan Kendra was established in 1980 to provide services to the under-privileged section of society. As there were no services for hearing impaired children in Jammu, a free school for such children was the first activity undertaken by the Society. Eventually it has broadened its services to provide vocational training for disabled people, advancement of rural technology, an anti-dowry program and several other projects to help destitute children and women.

The **Bishnah Block** comes under the Health Department of the State and was selected by the Samaj Kalyan Kendra to provide a comprehensive range of services including prevention of disability, strengthen existing referral services, public awareness programs for better utilization of services, training of village volunteers to extend the community based approach for detection and rehabilitation of people with disabilities. Emphasis was also given to infant feeding practices and various problems relating to it in a rural setting.

Bishnah Block is situated about 15 k.m. from Jammu and has a population of approximately 9,300 distributed over 121 villages. The block is on the India–Pakistan border. One third of the area is difficult terrain.

The Bishnah Block is divided into 10 sectors for easy monitoring. The work is done in collaboration with the PHC. A regular feature is the Sunday afternoon visits by medical experts to the Public Health Centres to examine children with disabilities who have been identified by the trained community volunteers.

The volunteers at the village level were selected with the help of the village head and other local officials. These community volunteers play a vital role in implementing the programme planned for the individual child on the basis of his or her disability. They also train the family members to help in the skill training of the child. The work of each volunteer is periodically monitored by the Supervisors who make surprise visits. When necessary, the children are referred to the Jammu Medical College.

To detect different types of impairments in children awareness programmes played an important role. These programmes are an ongoing part of the activities. Schools are also involved and awareness programmes on prevention of disabilities are conducted for teachers and students. Educational material is provided for display in schools, institutions, Government and non-government agencies. The community volunteers display them in their homes.

In the area of vocational training the individual is trained in the locality in which he lives. Some of them have found placements for being trained as weavers and tailors. The family is also encouraged to help in the process of rehabilitation. An orthotic workshop and vocational training workshop have been set up in Bishnah.

The Kendra's interaction with other NGOs and various Government agencies has resulted in provision of better and comprehensive services to children with various disabilities. Camps are periodically held in collaboration with other organisations catering to people with different disabilities.

Families who have children with disabilities are encouraged to interact with each other for mutual support. Very often they accompany each other to hospitals and other treatment centres.

The response of parents to the treatment given to their children vary. Some of them need a lot of motivation, particularly when they are from poor backgrounds and the degree of disability is severe. They need to be constantly persuaded to follow up the treatment. The parents tend to stop giving medication the moment they see the symptoms disappear and become careless.

For example– Many children with hearing impairments complained of 'running ears' or discharge for the ears. The moment some improvement was noticed in the children, the parents discontinued treatment and do not go back to the clinic.

The family's very survival for existence puts everything else in the shadow and the child with a disability is therefore doubly handicapped.

The success rate in following up the programme is higher in older children and children suffering from physical disabilities, as the Kendra has observed. The children themselves try to follow up the programme. Because they are directly benefited, they succeed in pressuring the parents.

The awareness programmes have had their impact on the community as have the improvements that can be seen in the children. The people have realised the importance of preventive measures. Pregnant women who had no idea about the need for immunisation are now asking for it. School children and teachers have become socially more conscious of the needs of children with disabilities.

10. PRACHAR (Program for Rural Awareness in Community and Rehabilitation) Kerala

The PRACHAR program of the Mar Gee Varghese Dionysius Memorial Hospital in the Kottayam district of Kerala began its work in 1986.

It aims at providing preventive, promotive, basic curative and community based rehabilitation services to the villages which he scattered in the mountain terrains of Idukki and Pathanamthitta, the plains of Kottayam and the water logged areas of Alappuzha district. Most of the villages are poor with very few households having even the basic facilities of latrines and safe drinking water.

One of the unique features of PRACHAR is its commitment to networking with other agencies working in the field; women groups, youth groups and others closely linked to the community. Such a networking has aided the integration of the social, economic and health aspects of rehabilitation. Together, these agencies are able to provide a variety of related services to a much larger number of disabled people. Recently project PRACHAR has also started working along with the Integrated Child Development Programs (ICDS) of the government, with the aim of strengthening community participation in the development and health of their children. The hope is that this partnership will go a long way in the prevention and early detection of disabilities amongst children.

The process of Rehabilitation

Grass root workers who are constantly in touch with the community identify people and children with disabilities. Assessment clinics are set up at various key locations so that people from the remotest areas can attend without a problem. At these clinics children and adults are assessed by specialists in collaboration with project PRACHAR is also actively involved in promoting integrated education for children with disabilities.

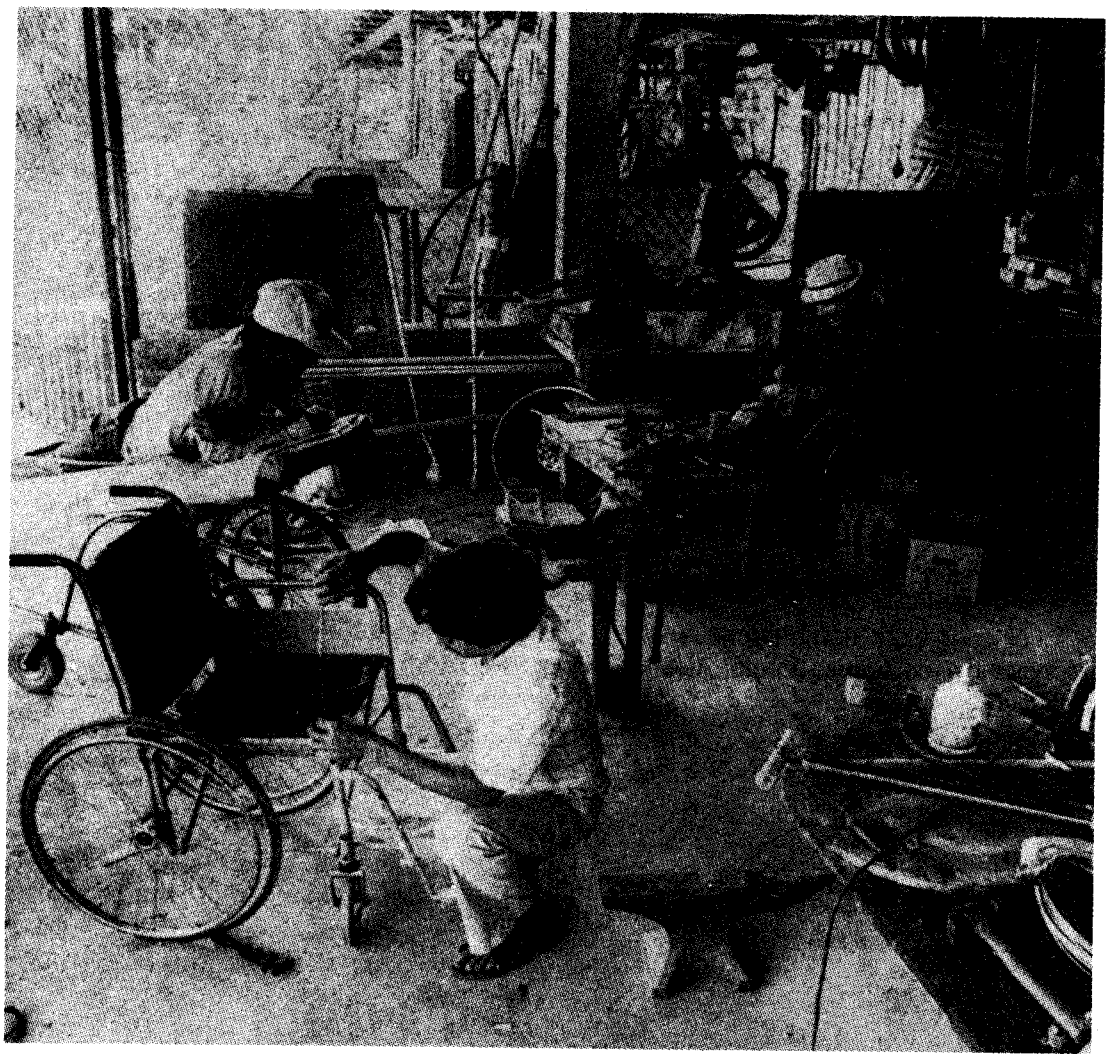
In keeping with its philosophy of networking with other agencies Project PRACHAR also helps disabled people make use of the many schemes that are available through the State and Central government; travel concessions, pensions for disabled people and schemes that help a disabled person get–work. All these are there but little known off in the remote parts of the country.

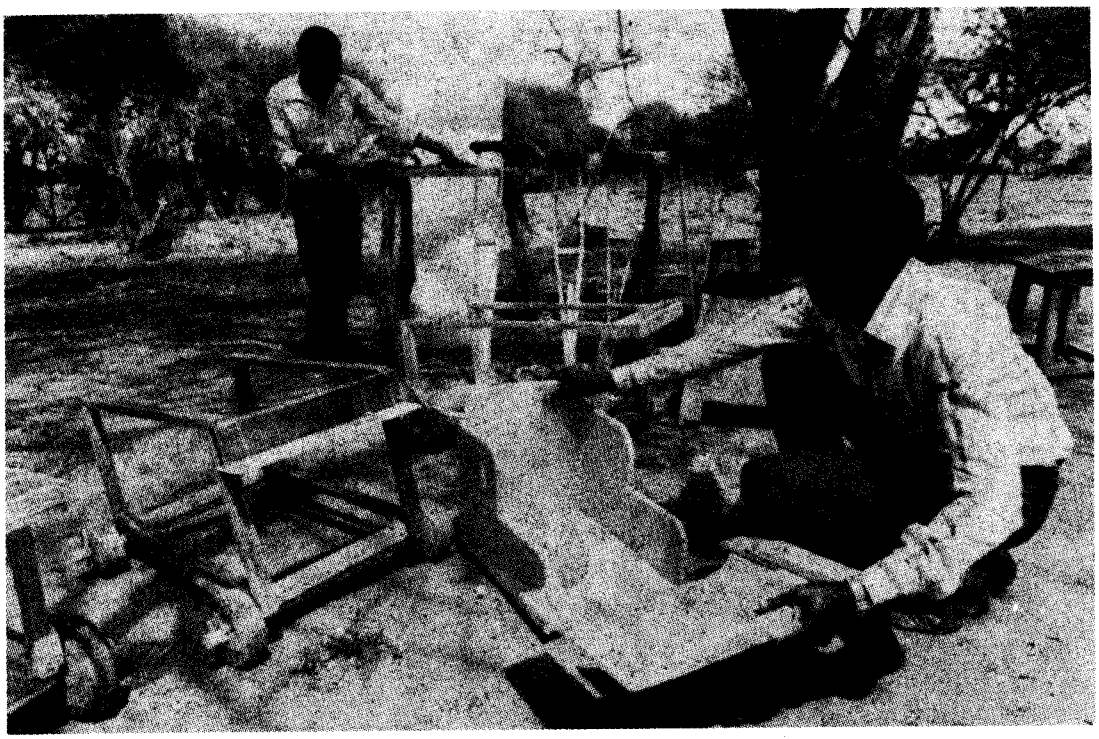
NOTES:

PART 3

WORKING IN THE SHOP

Rehabilitation Aids and Procedures





A lot of 'shop work' can be done outside. Here young men in Kibwezi, Kenya (Africa) learn to make low–cost aids. (Photo: *Aids for Living*, AHRTAG)

CHAPTER 57

Making Sure Aids and Procedures Do More Good than Harm

When I (David Werner) was about 10 years old, I was taken to a doctor because I was having problems with my feet. I kept falling over things and spraining my ankles. No one knew yet that these were early signs of a **progressive muscular atrophy.**

The doctor examined my feet. They were somewhat weak and floppy, so he prescribed arch supports. An **'orthotist'** across town would make them.

When the arch supports were ready, the orthotist put them on my feet. "Do they hurt?" he asked. "No," I said. So I was sent home with instructions to wear them every day.

I hated the things!–not because they hurt, but because it was harder for me to walk with them than without them. They pushed up on my arches and bent my ankles outward. I fell and sprained my ankles more than ever.

I tried to protest, but nobody listened to me. After all, I was only a child. "You have to get used to them!" I was told. "Who do you think knows best–you or the doctor?"

So mostly I suffered in silence. I took the arch supports out of my shoes and hid them whenever I could. But when I was caught I was punished. I was made to feel naughty and guilty for not doing what was 'best' for me.

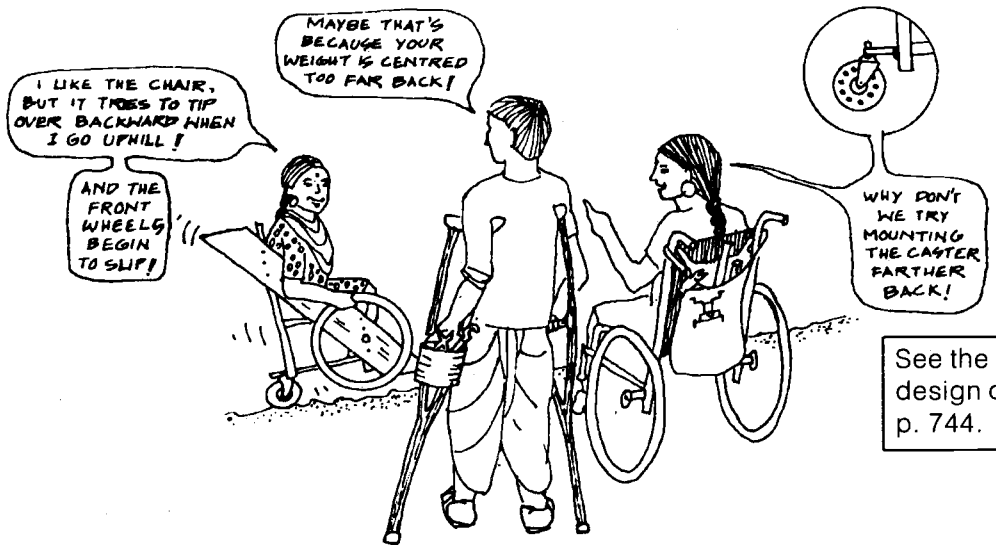
Several years later, as my walking continued to get worse, I was prescribed a pair of metal braces. They held my ankles firmly, but they were heavy, uncomfortable, and made me feel more awkward than ever. I hated them, but wore them because I was told to.

One holiday I took a long walk in the mountains. the braces rubbed the skin on the front of my legs so badly that deep, painful sores developed. I refused to wear them again.

It was not until many years later, long after I had begun to work with **disabled** children, that a brace maker and I figured out what kind of ankle support would best meet my needs. So now I use lightweight, plastic braces that provide both the flexibility and support that best suit me.

When I look back, I realize that **the doctor did not know more about what I needed than I knew.** After all, I was the one who lived with my feet! True, at age 10, I could not explain the mechanics and anatomy for what was happening. But I did have a sense of what helped me manage better and what did not. Maybe if the adults who were so eager to help had included me in deciding what I needed, I might have had aids that better met my needs. And I might not have felt so guilty and naughty for expressing my opinion.

I learned something from these childhood experiences. I learned how important it is to listen to the disabled child, to ask the child at every stage how she feels about an aid or an exercise, and to include the child and her parents in deciding what she needs. **The child and her parents my not always be right. But doctors, therapists, and *rehabilitation* workers are not always right either. By respecting each other's special knowledge and looking together for solutions, they can come closest to meeting the child's needs.**



See the design on p. 744.

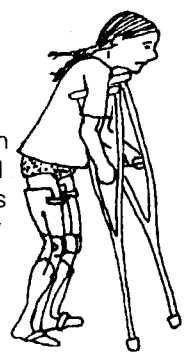
Some of the best design improvements in aids and equipment come from the ideas and suggestions of the children who try them out.

PRECAUTIONS IN PROVIDING A CHILD WITH AIDS, EQUIPMENT, AND PROCEDURES

To make sure aids and equipment really meet the child's needs, consider the following:

1. How necessary are the aids or equipment? Might it help the child more to learn to manage without them? For example:

Renuka has arthritis. Her thighs have become too weak to support her body weight, You can fit her with braces and crutches. But watch out! These aids will not make her thighs stronger. They may even make them weaker, since she could then walk without having to use her thigh *muscles.*



LESS APPROPRIATE

A better solution might be exercise to strengthen her thighs. For example, walking in water will make it easier for her legs to support her weight.



Also, using a cane instead of crutches helps her to use and strengthen her thigh muscles (see p. 712).



MORE APPROPRIATE

AVOID MAKING THE CHILD TOO DEPENDENT ON AIDS!

2. As any child grows and develops, his needs keep changing. **Frequent re-*evaluation* is necessary to find out if an aid should be changed or is no longer needed. Ask the child what he wants.** For example: (CP)

Arun has been slow to develop balance for sitting. At first, straps helped him sit in a stable, upright position.



APPROPRIATE ONLY AT FIRST

But as he continues to develop, keeping him strapped in a chair may keep him from improving his balance more or from learning to sit without help.



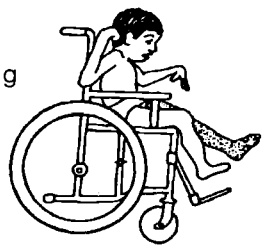
Arun might be helped more by a seat that gives support to his legs and hips but lets him balance the top part of his body without help (see p. 697).

APPROPRIATE LATER

Even after the aid is fitted it has to be checked and adjusted on a day to day basis. Parents, playmates and other people around the child can easily be given enough awareness to remove his discomfort an evaluate the aid.

3. **A simple, low-cost aid** that is designed and made to meet the needs of a particular child often works better than an expensive commercial one. For example: (CP)

Commercial wheelchairs are often too big for children, and hard to adapt to their positioning needs. Repairs are difficult and expensive; replacement parts are hard to get.



LESS APPROPRIATE

A simple wood or plywood chair can be easily made to fit the child's size and positioning needs. Repairs and replacements are easy because bicycle wheels and other standard parts are used. (See p. 748)

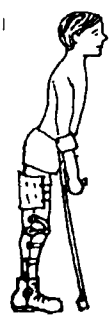


MORE APPROPRIATE

4. **Consider the economic limitations of the family and community.** Growing children will frequently need larger sizes of aids such as leg braces, artificial limbs, and special seating. **Use either aids that are cheap enough to replace often, or that can be easily made bigger.** For example:

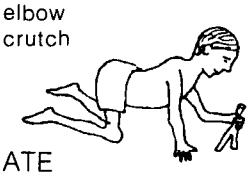
Poor families sometimes spend as much as a year's earnings on an expensive modern brace with knee and ankle hinges a special shoes.

When the child outgrows the brace, or it breaks, the family cannot afford to repair or replace it – so the child goes back to crawling, develops contractures and may never walk again.



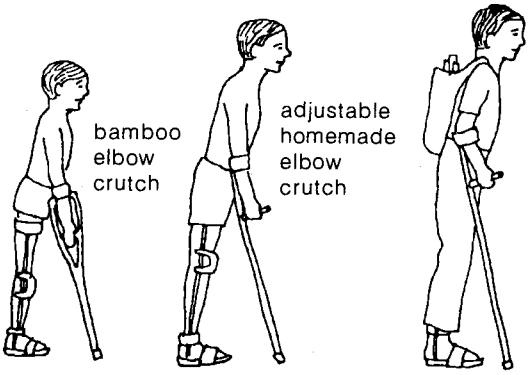
costly hinged brace with orthopedic boots

costly commercial elbow crutch



LESS APPROPRIATE

A cheap brace without hinges will not let the child bend his knee to sit. But the brace can be cheaply replaced, so the child is able to stay on his feet. Up to 20 low-cost braces can be made for the price of one expensive one.



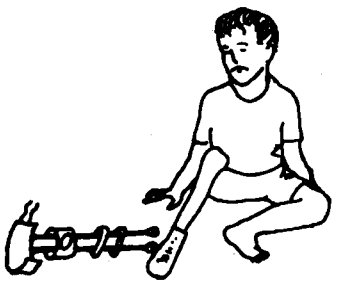
bamboo elbow crutch

adjustable homemade elbow crutch

MORE APPROPRIATE (See p. 663 and 711.)

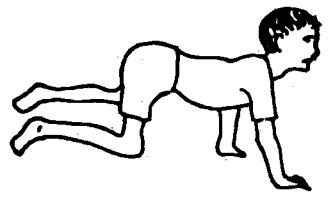
5. Try to provide services in and around the community so that an aid can be changed and repaired as soon as it needs to be changed and repaired.

Poor families may not have the resources or the time to travel long distances to get new aids, to change old ones that the child has out grown and to repair others.



Bhanus's brace broke while he was playing.

His father tied it up with old pieces of cloth but it kept opening up.

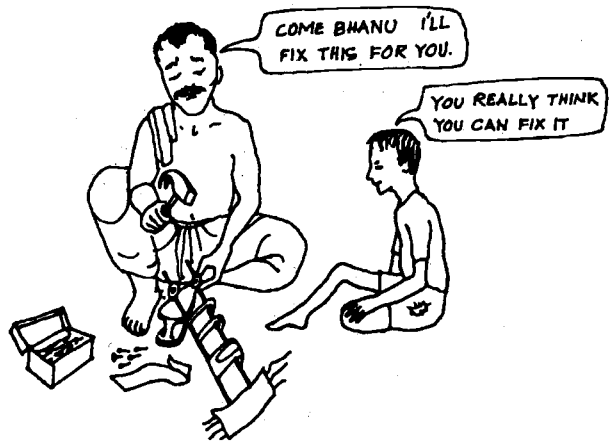


To get a new brace Bhanu will have travelled to city, fill forms and then comback again for the new brace. So the old broken brace was put away and Bhanu went back to crawling.

LESS APPROPRIATE



MORE APPROPRIATE

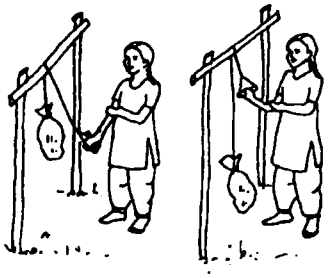


Rehabilitation centre near the village would be easier to go to. Or if some people in the village had been trained to make aids, it would be even better.

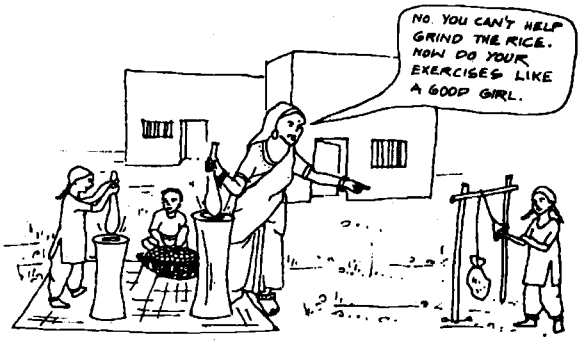
A simple and inexpensive thatched shed provides cover for this basket weaver who makes aids for the disabled in the village.

6. **Make use of the special opportunities in rural areas.** Look for ways that a child can do her exercises as part of daily work and play with other people–not as a boring chore that keeps her separate and different. For example:

If a child needs a special aid to strengthen her weak arm,



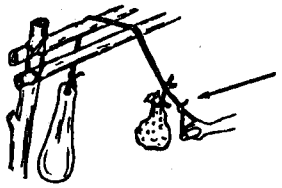
avoid making her do the exercise in a way that isolates her.



LESS APPROPRIATE

Instead, find ways for her to do her exercises while taking part in activities with others.

Another child can help lower the grinder.



If the grinder is too heavy to lift, you can put another weight here.



MORE APPROPRIATE

In places where people grind grain with a handmill, this can also be used for exercises. So can grinding grain on a stone dish. A mill can be adjusted from 'easy' to 'hard' (Also see pages 6 and 465.)



7. Whenever a choice can be made, **keep orthopedic aids as light and unnoticeable as possible.** For example:

Tina is from a village where most girls wear salwars. A rehabilitation center in the city fitted her with a heavy metal brace and boots like this. She hated them and refused to leave the house with them on because she could not wear her salwar over the metal braces. She had to wear shoes with the metal brace and shoes were not worn with salwars.





Six months later, Tina's father took her to a village rehabilitation center where they fitted her with a lightweight plastic brace. She could wear it under her salwar and still use her old sandals. She was happy to wear it anywhere.

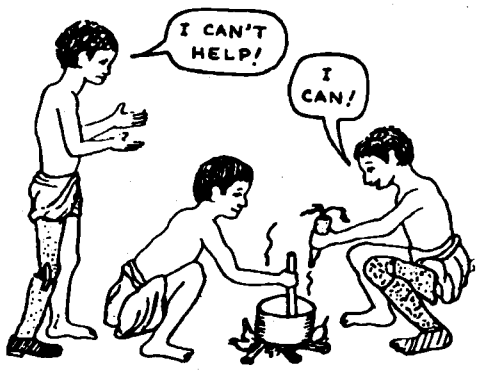


Note: In areas where children do not wear shoes and socks, a brace with a wood clog, leaving most of the foot open to the air, may be preferred (and may be cleaner).

8. **Try to adapt aids and equipment to the local culture and way of life.** An example of adaptation to the local situation is the 'Jaipur limb' (see also Chapter 68):

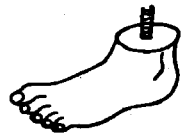
In our country, villagers squat a lot. They cook and eat at ground level. A person with a standard artificial leg cannot squat because the leg does not bend enough in the knee and ankle. Also, the standard leg is not made to be used when barefoot, or in water.

STANDARD LIMB *JAIPUR LIMB*



LESS APPROPRIATE MORE APPROPRIATE

The 'Jaipur limb' was designed for the needs of villagers in India. It has a knee with a joint that bends all the way. The foot piece is made mostly of rubber and is very flexible, allowing the person to squat. It is the color and shape (including toes) of a normal foot. It is waterproof, so that people can work in water or rice fields without harming it. The leg is low cost and quick to fit.



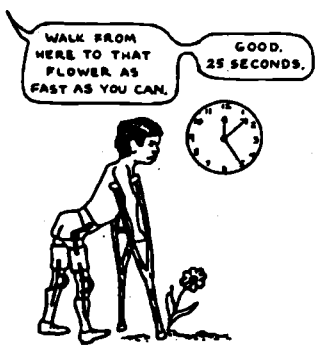
(For more information on the Jaipur limb, see p. 767.)

9. **Make aids and equipment as attractive and enjoyable as possible.** To test the attractiveness of an aid, find out:

- Does the child take pleasure or pride in his aid?
- Do the parents like it?
- Do other children want to use it or play with it?



10. A common error is to provide children with more bracing than they need. Often a child will come to the rehabilitation center already fitted with big heavy braces that he never needed or no longer needs. They may actually slow him down. **Always check to see what a child can do with and without his aids. Try smaller, lighter aids, or none at all. Above all, ask the child what he prefers.**



LESS APPROPRIATE



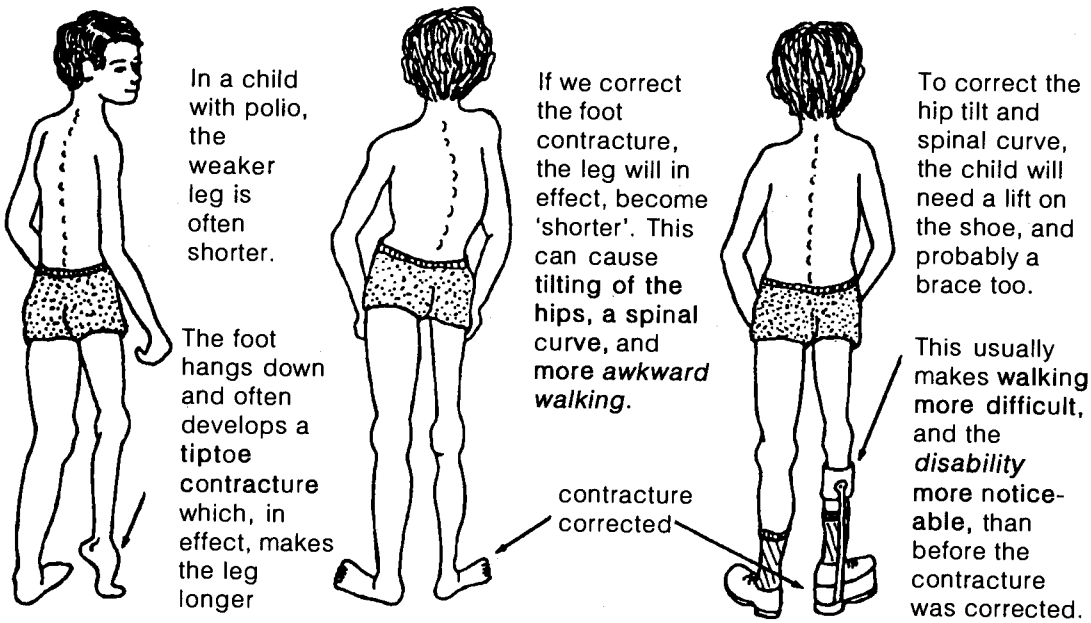
MORE APPROPRIATE



STILL MORE APPROPRIATE (for this child) (See p. 670.)

EVALUATING WHICH DEFORMITIES SHOULD BE CORRECTED AND WHICH SHOULD NOT

PART 3 of this book, in addition to aids and equipment, also discusses methods for correcting joint contractures, which are discussed in Chapter 60. Just as you need to decide if a brace is appropriate, **you need to decide whether correcting a contracture will actually help a child.** Although many contractures increase difficulty for a child, some may actually help and should be left uncorrected. For example:



For this child it may be best NOT to correct the contracture.

Other examples of contractures that are sometimes more beneficial than harmful are finger contractures in persons with hand ***paralysis*** (see p. 214) and tightness of back muscles in parsons with ***spinal cord*** injury or muscular ***dystrophy*** (see p. 463).

(CP)

CAUTION : In children with spastic cerebral palsy, sometimes orthopedic surgeons perform operations to correct contractures or awkward positions, without completely evaluating the effects on the children. Often children find it harder to walk or function after the surgery. **Always seek the opinion of therapists and other orthopedists before deciding to have the operation.**



Before deciding to correct any contractures or deformities, try to be sure that the correction will help the child to do things better.

WHAT IS MORE IMPORTANT—APPEARANCE OR FUNCTION?

When a choice needs to be made between an aid that is more useful and one that is more attractive (or perhaps no aid at all), it is important to **consider the cultural factors** and to respect the **wishes of the child and her parents.** Here is another story.

A HELPING HAND FOR SRI

When Sri was 13 years old, one day she was helping her father at a small sugar-cane mill that was pulled round and round by a mule. Her hand got caught in the gears of the mill and was crushed. It had to be cut off at the wrist.

The stump healed quickly, but Sri's spirit did not. It seemed as though it, too, had been crushed. She had been a happy girl. Now she just sat around. She did not help with house-work, and refused to go outside. She kept her stump hidden in her clothing or behind her back.

Sri's family worried about her. They took her to a specialist in the city who examined her and suggested an artificial limb. She gave Sri the choice between hooks, which would be useful, and an artificial hand, which looked more natural but would be less useful. The specialist encouraged her to choose the hooks, and explained how well she could learn to use them. But Sri picked the hand.



The hand was very expensive, but it looked almost real, and the family agreed. Her father had to sell his mule to pay for it, and was in debt for more than a year.

As time went by, however, Sri never really used her new hand. She tried it on a few times, but it seemed cold and dead. One day when her mother took her to the market wearing the hand, Sri thought everyone was looking at her. Two little boys, who had been her friends, pointed at the hand and laughed. She never wore it again.

One day a village health worker visited Sri's home. She saw that everyone was busy working and doing things except Sri, who sat quietly in the corner.

After talking with her family, the health worker suggested that they make an effort to treat Sri just like the other children.

"Encourage her to help with work, and to take part in all your activities," she said, "Don't pretend that Sri's hand isn't missing. Just accept her as she is. Let her know that you love her and need her help as much as before."

So instead of feeling sorry for Sri, or letting her just sit and feel sorry for herself, her family began to treat her as they had before the accident. They asked her to help with the house work, prepare the meals, and care for the baby. At first Sri was unwilling and found everything difficult. But soon she learned how to do many things by using her good hand and her stump. She began to gain new confidence in herself and in time started going to the market alone. At first, people took notice of her missing hand, or whispered, "Oh, poor thing!" But when they saw how well she did things, they soon stopped feeling sorry for her and began to treat her like any other person.

NO



It is important that the family not let the disabled person be separated from daily work and activities.

YES



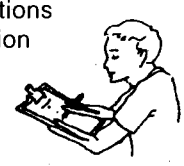
Instead, look for ways to let the disabled person help as best she can.

When trying to decide about an aid, we need to seek the balance between usefulness and attractiveness that helps the child fit in best with his or her family and community.

Rehabilitation experts often place great importance on usefulness, or 'function'. But acceptance in the community is also very important. So before trying to convince a child like Sri to accept an aid that will make her deformity more noticeable, we must consider how this could affect her. In some communities, people will soon accept both the child and her aid. But in some societies, people have beliefs or deep fears about a person whose body is 'incomplete', In other societies, amputation of a hand has traditionally been the punishment, and sign, of a thief. Or a girl who is seen as defective may not be likely to find a husband. So, it may be socially very important for her to have an aid that looks real or is less noticeable, even if it does not function. (If the family can afford them, sometimes the best solution is 2 artificial limbs–hooks for home use or work, and a 'hand' for 'dressing up' and going out.)

APPEARANCE CAN BE IMPORTANT

For example; one of the most useful solutions to amputations of both hands is an operation which uses the two bones of the lower arm to create 'pinchers'. The operation is fairly simple for an orthopedic surgeon, and once completed no aids are needed for grasping and handling a wide variety of things. The biggest advantage is that **the person can feel what he handles.** But few people choose this alternative because, they say, it looks so strange.



It is, of course, unfortunate that a child feels ashamed or thinks she has to hide her disability. We must work for greater understanding. But people do not change their attitudes quickly. Often the child and her parents have good reasons for their fears, and we must learn to accept them. However, we must also help the child, her family, and the community to become more accepting of the child's disability and to provide as many opportunities for the child as possible.

We need to help the child find courage. A child with a new disability will often be afraid to go out into the community, or back to school. And other persons or children may at first take notice and 'feel sorry' for her–or even tease her. But if she can be helped through this first difficult period, usually other people and children will soon get used to her 'difference' and accept both it and her. As more disabled persons find the courage to go out into the community it will be easier for those who follow, because people will become more open and accepting.

In the story of Sri, the rehabilitation specialist tried to solve her problem by giving her an artificial limb. Her family spent a lot of money on t. But the new 'hand' did not solve her problem. She never really accepted or used it. Her problem, which was partly emotional, was finally solved by the whole family helping her to join them again in daily activities, and to gain new confidence in herself.

This is very important. **Too often we try to find technical answers to problems that are mostly personal, social, or emotional.** So we turn to special aids and equipment. Sometimes these are needed. But sometimes they are unnecessary, too costly, or make life more difficult for the child (even though they may be of some help physically). So....

Before deciding if a child needs special aids, braces, surgery, or equipment, and what kind, carefully consider the needs of the whole child within her family and community.

Inspite of modern material being used for making aids and appliances for disabled people, the problem of rejection by disabled children, specially in the rural set-up remains very common. Cause of the breakages, deformations, mechanical and structural failures in the materials used, due to irregular stresses caused by uneven country roads and also because of illfitting appliances have not been assessed. Disabled children living in the rural areas face difficulties when they need their appliances to be adjusted or repaired.

Artificial aids for disabled people can be made inexpensive and appropriate by using locally available materials. A visit to a junk yard can also offer many ideas for making aids with junk material, aids such as braces and collars. Coconut shells are good for making joints. Some other material is steel pipes.

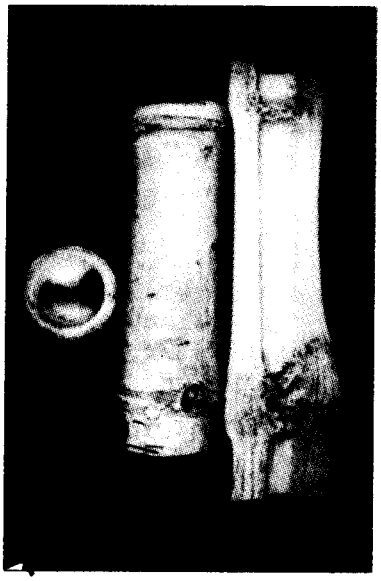
The use of BAMBOO for making aids and appliances.

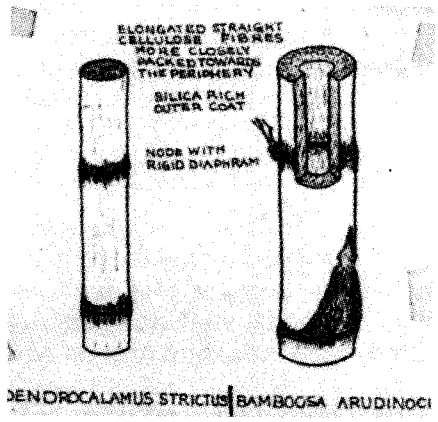
Bamboo has proved to be one of the cheapest, sturdiest and most readily available materials in nature for making aids and appliances. The strength of the bamboo varies for different types. **Bamboo can be be bent, slit or straigtened.** Its technical qualities make it a very durable material, particularly **LATHI BANS, (Dendrocalmus Strictus) and COMMON BAMBOO (Bamboosa Arundinacea), available in many parts of our country.**

Various portions of the above mentioned varieties of bamboo can be used for making a wide range of aids appliances such as **splints, crutches, braces, wheel chairs, walkers, artificial limbs etc.**(See chapter 58 for how to set up a workshop for making aids and appliances.)

Slitting of bamboo

Only certain portions of the bamboo can be slit. Greater the diametre of bamboo, the greater is the width of the flat portion available for use. Some proportion of the bamboo has to be filed or turned for cosmetic finish.



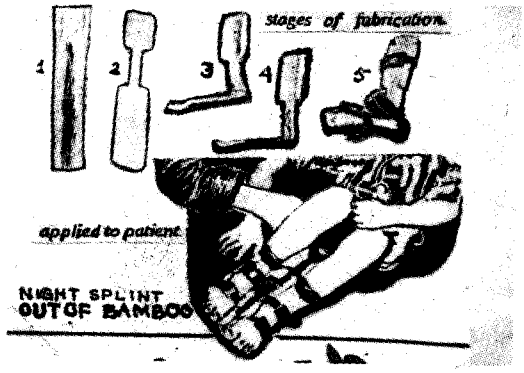


Bending of bamboo by Melting

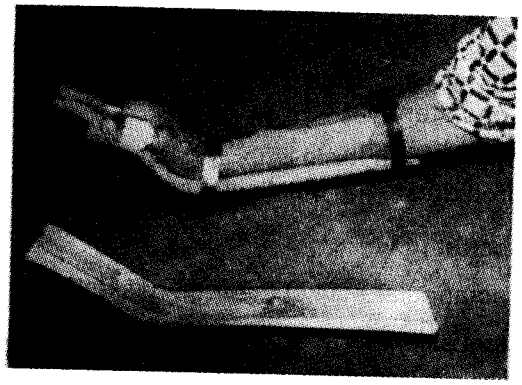
Bamboo becomes very pliable when it is heated and while hot it can be molded to any shape needed.

To do this, the bamboo is first clamped in a vice and then heat is applied using a lamp at the point where it needs to be bent. When it becomes red hot, it is bent and then cooled by immersing it in cold water.

Aids made from bamboo



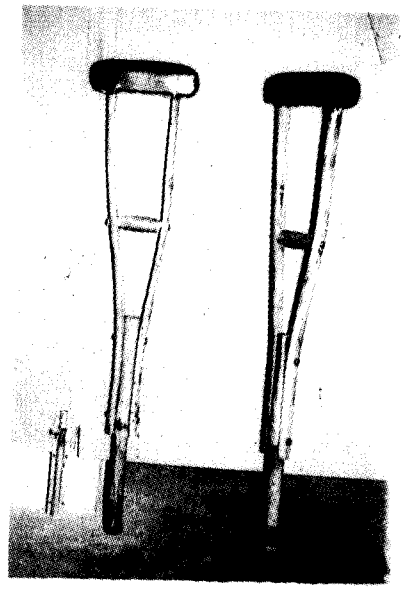
Bamboo **night splint** showing the different stages of fabrication and then applied to a child's legs to prevent rotation of the foot.
Time of fabrication: 45 minutes
Weight: 200 grams
Cost : Rs. 20.



Volkmans Splint prevents deformities of the wrist drop and contractures.
Fabrication time: 30 minutes
Weight : 60 grams
Cost : Rs. 20.

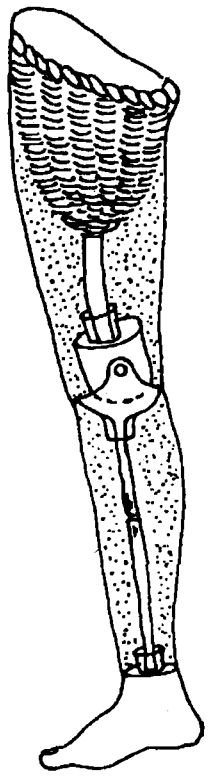


Walker made from bamboo — A durable mobility aid.



Crutches is another durable and inexpensive aid made from slit bamboo.
Fabrication time : 45 minutes.

Advantages of an Artificial Limb made from bamboo



Consistency

Soft, like a normal limb. It has a lurch due to the elasticity of cane/bamboo.

Socket

Rectangular socket made of basket (cane), lined by sponge.

Permission aeration of amputated stump while walking.

No Sweating. It is specially advantageous for tropics.

Body of thigh

Soft. Covered by rubberised stockinette and sponge.

Skelton is made of bamboo or cane.

Knee joint

Made of bamboo or coconut shell. Single axis joint.

Control on motion due to a spring unit which gives resistance to motion; enables the leg to move harmonically and normally.

Shin

Demountable clip type of joints for cane or bamboo shin.

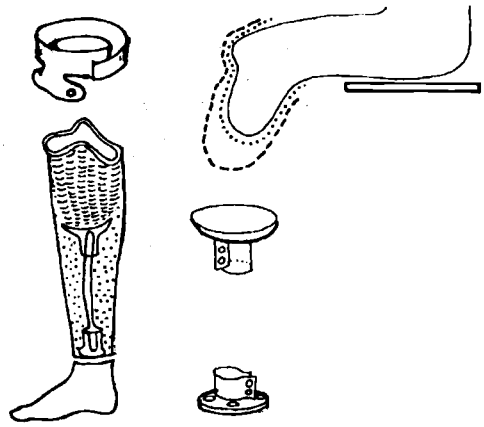
Foot

Jaipur style foot adds to the versatility of the limb.

All movements possible to a limit.

Use of irregular roads

Stress and strain on rough roads much less due to the elasticity of cane.



For more information on how to make lowcost aids and appliances (especially from bamboo) contact: Dr.J.B. Banerjee, Viklang Kendra, 13,Lukerganj, Allahabad, U.P.

CHAPTER 58

A 'Shop for Making Aids' Run by Disabled Villagers

In PART 2 of this book we talked about the value of village based ***rehabilitation*** centers run by local disabled village workers.

One important feature of such a center is a simple but adequately equipped shop for making basic ***orthopedic*** equipment and ***rehabilitation*** aids at low cost. The shop also gives disabled persons a chance to learn useful skills, to earn some money, and to be good examples for other disabled children and their families.

There is no formula for how big the shop should be or what it should include. **often it is best to start small but to leave room for growth.**



Disabled villagers at work in shop – PROJIMO, Mexico.

A **'rehab shop'** might include areas and equipment for may or all of the following activities :

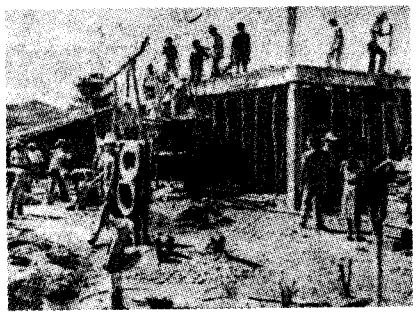
- **plaster casting** for correcting contractures and club feet
- **brace (caliper) making** using metal, plastic, or both
- **woodworking**— for making crutches, walkers, lying and standing frames, special seating, wooden wheelchairs
- **welding and metalwork** for making and repairing wheelchairs and other metal aids.
- **leatherwork** for making brace straps, *adaptations* for shoes and sandals, and knee pieces
- **sewing** (with machine if possible) for wheelchair seats, straps, special clothes, and other articles
- **artificial limb making** – for making simple bamboo or leather limbs and perhaps more complex ones of wood, aluminum, or resin.
- **game and toy making** (or this can be done in a separate 'children's workshop'. See Chapter 50).

Income–producing activities as a part of the shop function

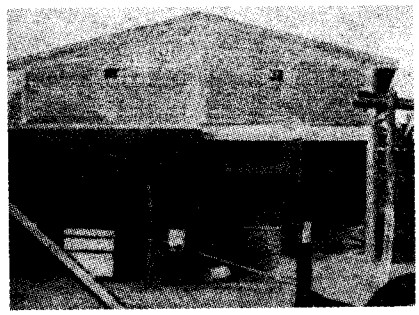
The skills and tools for welding, woodworking, sewing, and leatherworking can also be used to make things other than those needed for rehabilitation. The village shop and its workers can make things that can be sold to help pay for program costs.

For example, disabled workers in the shop of PROJIMO in Mexico make metal framed chairs with woven plastic seats, sandals with auto tyre soles, and silk–screened goods such as bags, T–shirts, and aprons. The shop also provides welding or repair services for plows, bicycles, machinery, shoes, and many other things. Selling these things and asking small charges for repair services brings in some money to the program, helping it toward self–sufficiency. It also provides training and work experience for disabled workers who may later choose to work independently.

However, caution **must be taken not to try to do too many things in one workshop**– especially if space is limited. It can easily become too disorganized.



Villagers and visiting students building the PROJIMO workshop



The completed workshop — at the edge of the playground.

The building

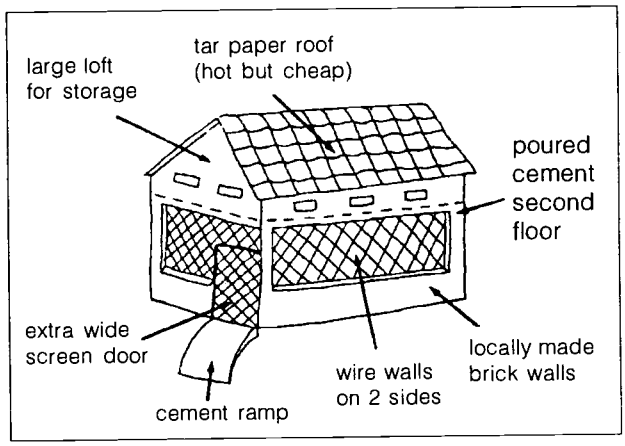
You may have to start with whatever space or building you can find. If you have enough funding or community cooperation (or both) you may be able to build a shop. However, **it is often best to start in some old rented or borrowed building, and not build your own shop until you have experience and a better idea of just what you need.**

Three things are important:

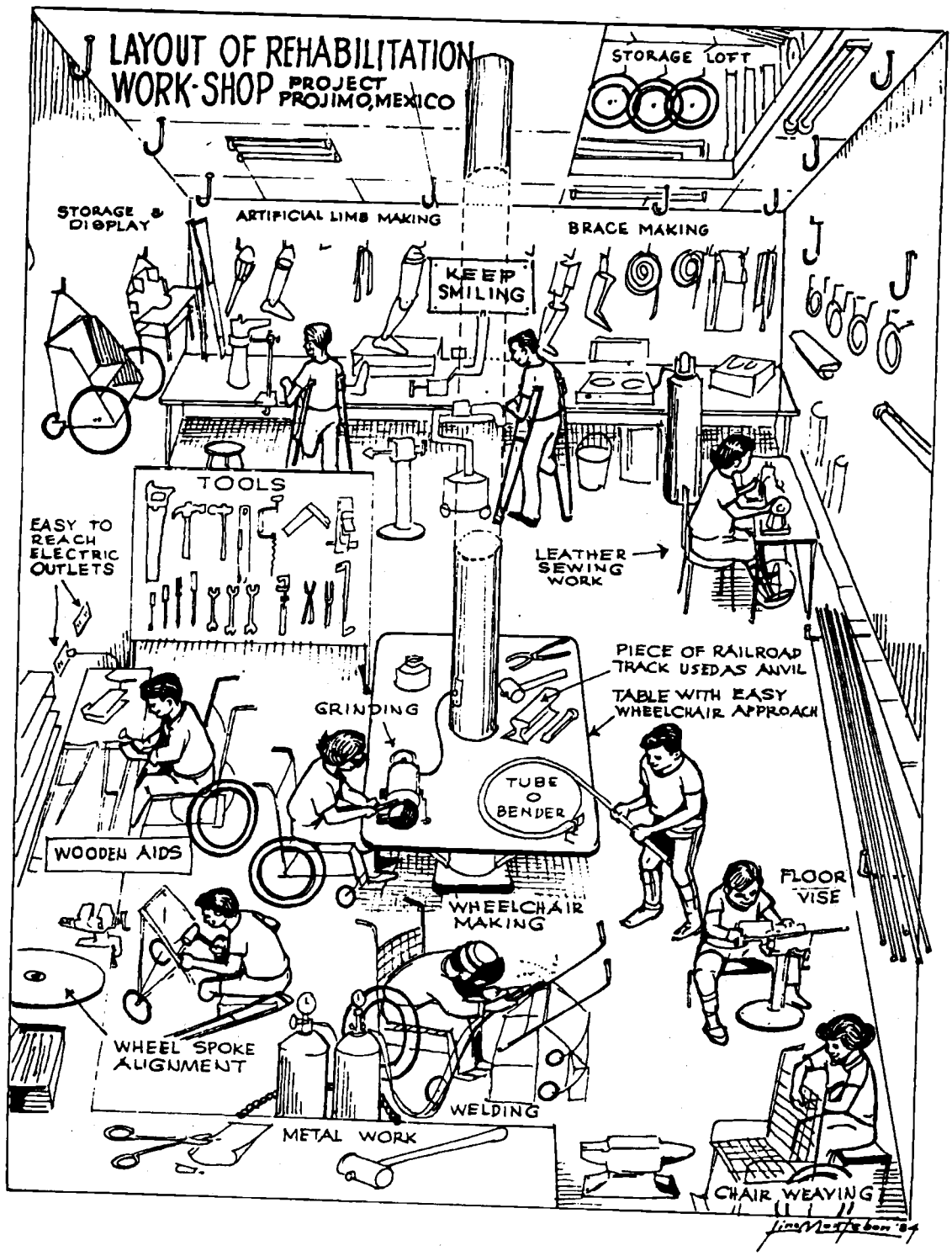
1. **Try to put the shop close enough** to the rest of the rehabilitation center for convenience, yet **far enough** away so that shop **noise** does not disturb discussions and therapy with children and their families.

2. In hot climates especially, make sure the shop is **well ventilated** (allows air movement). A roof with one or more walls that are open, except for bars or fencing, works well.

3. Be sure there is plenty of **storage space.** This is especially important if old braces, wheelchairs, bicycles, and other used equipment are collected for used parts, to save money.



The PROJIMO workshop first opened on the back porch of an old house. A year later a new shop was designed and built with community participation, and some outside funding. It is 8 x 12 meters. Two walls are screened, on the sides the rain is least likely to blow in. A large loft provides storage space and helps to keep the work area below cooler. The new shop is already too small!


LAYOUT OF REHABILITATION WORK-SHOP PROJECT PROJIMO, MEXICO
STORAGE LOFT
STORAGE & DISPLAY
ARTIFICIAL LIMB MAKING
BRACE MAKING
KEEP SMILING
TOOLS
EASY TO REACH ELECTRIC OUTLETS
LEATHER SEWING WORK
PIECE OF RAILROAD TRACK USED AS ANVIL
TABLE WITH EASY WHEELCHAIR APPROACH
GRINDING
TUBE BENDER
WOODEN AIDS
FLOOR VISE
WHEELCHAIR MAKING
WHEEL SPOKE ALIGNMENT
WELDING
METAL WORK
CHAIR WEAVING

Arrangement of work space

Each program needs to plan its own use of space. However, a few things are important if persons in wheelchairs will be workers:

- Enough **space** should be allowed everywhere for 2 wheelchairs to pass each other.
- At least some of the **workbenches** should be low enough to work at from a wheelchair or stool. Build them so that wheelchairs can get close to or under them with as few obstacles as possible.
- **Tool and supplies** should be stored **within easy reach of** workers in wheelchairs. Also, switches and power outlets.

The drawing on p. 651 show how the workshop of PROJIMO is arranged. We include it as an example, Not as a model.



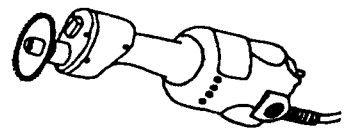
Photo: Richard Parker, PROJIMO

Tools and equipment

What is needed will depend on what activities the shop includes, how simple or complex is the technology used for each activity, and whether or not electric power and tools are available. **Nearly all aids can be made of local materials with hand tools,** and without electricity. Even wheelchairs, if made of wood, can be built with few tools or equipment. The small amount of welding required for axles could perhaps be done by the nearest welding or auto repair shop. However, **having a few time–and effort–saving tools can make work easier, faster, and more enjoyable:** a sewing machine, a grinding wheel (whether hand crank or electric), and a gas or electric stove (to heat plastic for braces). Welding equipment or a blacksmith's forge and bellows makes possible the production of many things.

Basic tools and equipment for the shop will be discussed in more detail in this section of the book, PART 3, the chapters of which described making different kinds of aids.

One very expensive but important piece of equipment is an **electric cast cutter.** It is an extremely useful tool for removing plaster casts and for cutting molded plastic braces from plaster forms. It is also a relatively safe tool, because the blade vibrates but does not turn, so it cuts hard things like plaster more easily than soft things like skin and flesh.



Training for shop skills

Possible ways for learning different shop skills were discussed in Chapter 55. Here we will only repeat that **one of the best ways to learn shop skills is through 'apprenticeship',** or learning–by–doing under the guidance of someone with more experience. Perhaps local craftpersons, such as carpenters, welders, and shoemakers would be willing to help teach members of the team. If the team has one or two persons with basic crafts experience, they can teach the others. For brace and limb making, it may help if one of the rehabilitation team has a chance to visit and learn in an orthotics and *prosthetics* shop. Or perhaps a skilled brace or limb maker can come for a few weeks to help set up shop, obtain basic materials, and teach the local team.

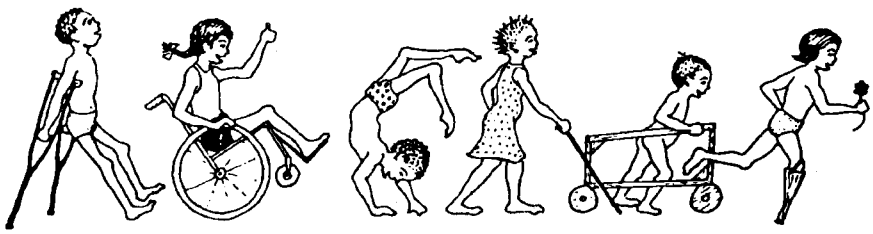
With an active, learning–by–doing approach, together with hard work to meet daily needs, team members can quickly become relatively skillful. On the other hand, if the team is made up, at least in part, of young disabled persons who have never worked before or cooperated as members of a team, both learning and work may at first progress more slowly.

Management and job assignment

How work is organized in the shop, and who organizes it, are decisions that need to be carefully discussed and decided by the group. Some programs have someone acting as 'boss' or 'foreman' who assigns each person a job. This may be more efficient. But programs that are 'people centered' prefer a more cooperative approach, where the whole group is involved in making key decisions. With such an approach, a coordinator may be chosen (or different coordinators can be chosen for different responsibilities). The coordinator does not give orders, but rather takes orders from the group. This approach is usually less efficient and more confusing. However, it is more enjoyable. Workers tend to take more interest, responsibility, initiative (and time off) than they do under a boss.

Also, the team needs to decide about how work is divided, and who does what jobs. Some workshops employing disabled persons use an 'assembly line' approach. Each person does a simple, repetitive job, such as cutting out one piece of tubing time after time or putting spokes into wheels. This approach requires relatively little training for each worker. mentally retarded workers who learn by repeating something over and over again often do well working this way.

However, **most people work better when they are able to make something from beginning to end.** Then they can share the satisfaction of a child and her family when a wheelchair or brace or toy they made looks nice and works well. In PROJIMO, whenever possible, workers (individually or in pairs) are responsible for the complete production of an aid. They start by helping to evaluate the child's needs and end by seeing how well the finished aid meets those needs. This way, each worker can see the personal value of each aid that he or she makes. This approach may be less efficient, but it is more satisfying. Thus the team watches the results rather than the clock, and works first for the people, not the money. This personalized approach is very important to a program designed to serve those in greatest need.



PART 3 of this book provides information on two main areas: (1) non-surgical orthopedic procedures (straightening contractures and club feet with casts), and (2) the production of low-cost rehabilitation aids. All of these things can be done in a village-based workshop such as the one just described. However, many of the aids can also easily be made at home by the family of the child.

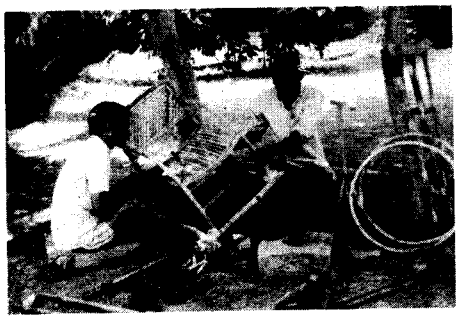
To encourage family participation in making aids, and later repairing them, mothers, fathers, sisters, or brothers can be invited to the shop to help build the aid. Or disabled children can help make their own aids. Some of the best workers in the PROJIMO workshop today began as young people who helped make their own crutches or wheelchairs–and then began to help make aids for others.

The ideal is that everyone does what they can to help and learn from each other: one big, human family working together and enjoying each other.

Here are two examples of shops for making aids that have been set up by two voluntary organisations providing need based low cost aids and appliances to people with disabilities. One example illustrates the growth of a workshop, using local **resources**. The other is an example of a network of workshops.

Viklang Kendra (Allahabad)

Viklang Kendra's now well established workshop for making aids evolved from an effort that started under a tree . It used the talents of the local artisans and other craftspeople and increased the effectiveness of their creative skills. Their knowledge of using local material was reinforced by blending it with modern technology. This process is called the **Tin Shed Technology**. Today Viklang Kendra manufactures a wide variety of aids and appliances to suit individual needs using the skills of these crafts people in its well equipped workshop.



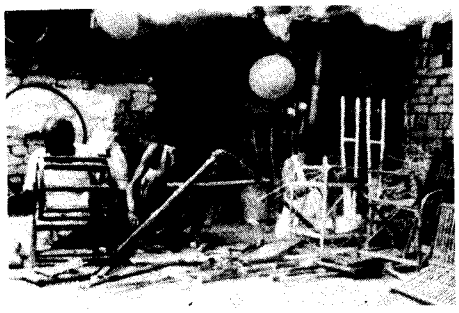
It started under a tree.The basket maker learns to make aids.



A shed with a thatched roof was put up to give shelter to the growing services.

Basket makers already have simple tools that can be used to make aids and appliances for disabled people.

Gradually disabled people were trained to make furniture, baskets, mats etc. which they could sell. Not only was this therapy for their hands, but they also learned a trade which could earn them a better living.



The village basket maker working on an Aid – The crutches have also been made by him.



The workshop evolves further, by manufacturing aids needed for physio and occupational therapy.

Once more money was available for establishing a more specialised workshop, tools and other machinary were bought.Selected village artisans were trained as multipurpose rehabilitation workers. Aids were then made with the help of other artisans and technicians.

Just like the basket maker, every village has, carpenters, cycle repairers, blacksmiths and shoe makers. The skills of these people can be used for making aids on an "if and when" basis. Their services can be used in the beginning for establishing a gradually growing workshop.

People who helped in the manufacture of these aids and appliances were :

- **Cycle mechanics:** To repair wheel chairs and cycles.
- **Plaster Technicians** : To make plaster casts for correction of deformities.
- **Bamboo basket workers and carpenters** : To make braces, using bamboo, wood, material, plastic or any other material. These people also make toys.(see chapter on toys)
- **Wooden wheel makers** : To make castors and handrims for wheel chairs. (Viklang Kendra got the help of old bullock cart wheel makers to make wooden castors).
- **Tailor** : To sew belts, slings, straps and wheel chair seats.
- **Limb maker** : A limb maker was hired for a short period of time to train people (including those with mental handicap) within the workshop to make limbs.
- **Shoe maker** : To make sandals, clogs, shoes and shoe straps, and other leather work needed for aids.

The village masseur was trained to give progressive muscle and joint stretching exercises.

Potters People working with clay were taught to act as therapists. Through modelling they taught coordination exercises to people with hand problems.

To make the workshops function usefully, various disciplines were gradually introduced. Constant interaction between patients, artisans, therapists and village level workers supported by visiting rehabilitation engineers, clinicians and therapists added to the smooth running of the workshop.

Building a network or rehabilitation

CERTH INDIA (Centre for Education,Rehabilitation and Treatment of the Handicapped), supported by Handicapped International started an orthopaedic workshop for rehabilitating children affected by polio. Later, many local institutions who were interested in the program were strengthened to work with each other in starting peripheral units. A system was evolved which could reach the whole region. A central workshop could be linked with several satellite workshops started by different voluntary organisations in a particular region.

The aim of the venture was to produce simple orthopedic appliances using locally available materials like leather, wood, rubber, bamboo, metal and used tyres.

A Central Workshop (CERTH India's Orthopedic unit at Pondicherry).

The functions of the central workshop are:

- To develop links with other local organisations and government departments.
- To develop and provide care for children affected by polio, living in the urban and surrounding rural areas.
- To produce of PVC shells, polypropeline foot pieces, metal hinges for its own use, as well as to sell to other small units.

The central workshop has trained personnel such as the physio or occupational therapist and is the plaace where children with difficult problems can be referred to.

The peripheral workshop

(for example The Gandhi Rural Rehabilitation Centre, Alampoondi)

The peripheral workshops are run by local organisations at a distance of about 30 to 100 kilometres from the central workshop. They should be financially independent. With a small investment of about 12,000 rupees, such units can fabricate braces using ready made parts bought from the central workshop.

Units without a workshop

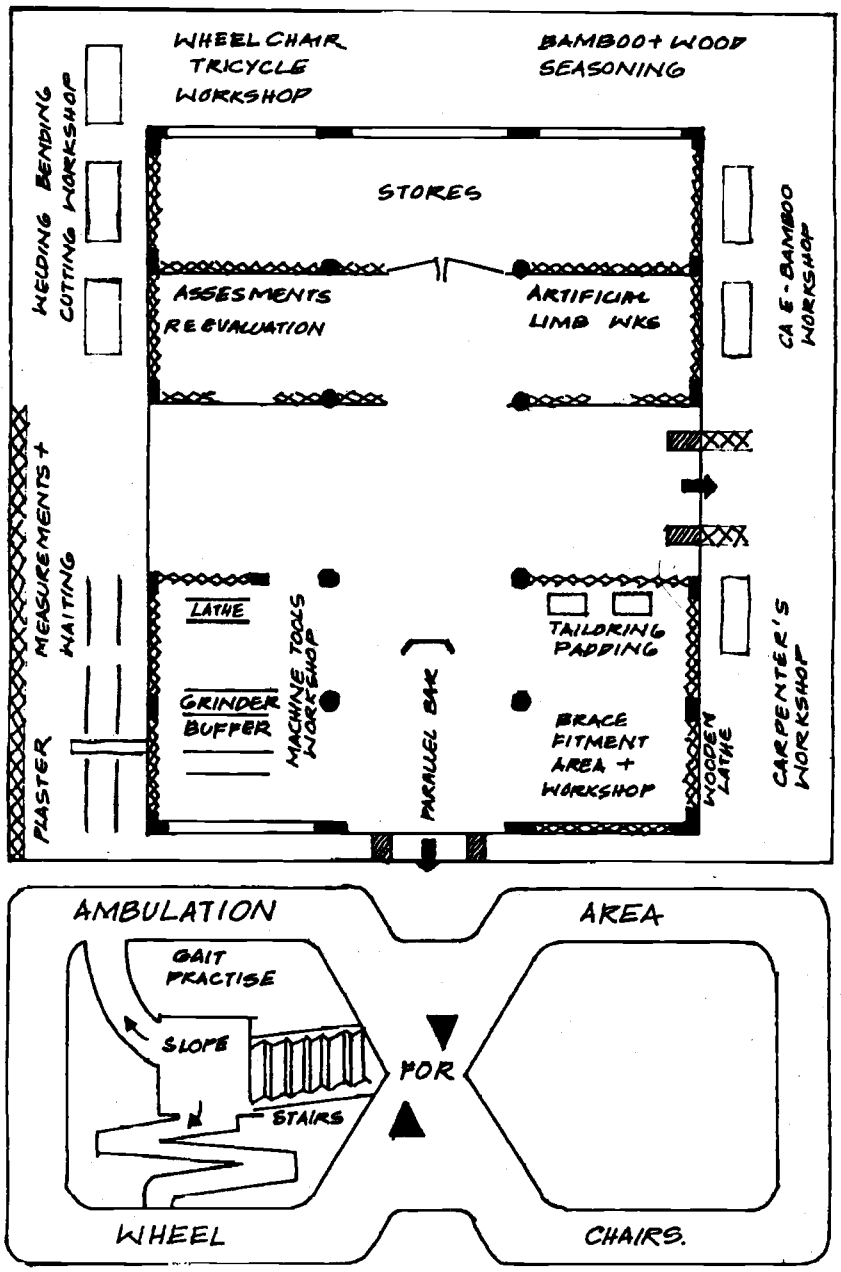
Some organisations may prefer not to establish their own workshop but want to provide rehabilitation services in their area with help from the central and peripheral workshops for fitting of aids and appliances.

The mobile technical unit

If an organisation can provide physiotherapy but not the aid, then a mobile van equipped with facilities to produce appliances can be sent from the central workshop with a team of technicians.

LAYOUT OF VIKLANG KENDRA'S EVOLVING REHABILITAION WORKSHOP

LAYOUT OF VIKLANG KENDRA'S
EVOLVING REHABILITAION WORKSHOP



In the evolving process of the TIN – SHED TECHNOLOGY,the disciplines that take more space are placed in the verandah (corridor) around the "Tin–shed" while those that need protection are placed inside. The ambulation area which forms the most important aspect of the delivery of aids is placed outside so that there is enough area for training the users of the aids.

NOTES:

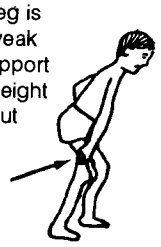
CHAPTER **59**

Braces (Calipers)

Braces are aids that help hold legs or other parts of the body in useful positions. They usually serve one or both of **2 purposes:**

1. **To provide support or firmness to a weak joint (or joints). For example, this child had polio:**

His leg is too weak to support his weight without help



This brace keeps his knee from bending forward



2. **To help prevent or correct deformity or contracture. For example, this child had a club foot:**



He was born with a club foot.



His club foot was corrected with a cast.

After correction, his foot is kept in a good position with a brace.



CAUTION: The need for braces should be carefully evaluated. Braces should be used only if they will help the child move better and become more independent. Too much bracing may actually weaken *muscles* and cause greater *disability*. As a general rule, **try to use as little and as light bracing as possible to help the child *function* better.** (See Chapter 57).

Different braces for different needs

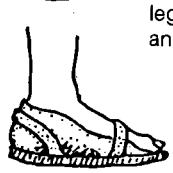
The main lower-limb brace types are:

Foot brace

usually made of molded plastic

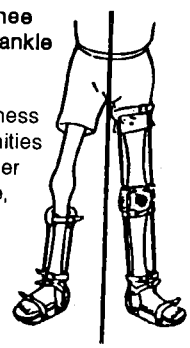


for deformities in the foot (not ankle) such as severe flat foot



Below-knee braces (ankle brace)

for weakness or deformities in the lower leg, ankle, and foot



Above-knee brace (long-leg brace)

for weakness in the upper leg and knee–possibly also ankle and foot

Above-knee brace with a hip–band

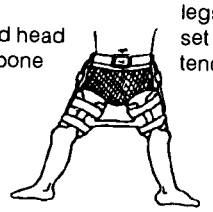
for severe weakness in hips and legs



Less commonly used types (described on p. 667 and p. 678) include:

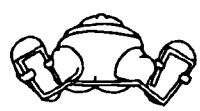
Leg-separating braces

for *dislocated* hips or damaged head of thigh bone (See p.)



Foot-*positioning* night brace

for holding the feet, legs and hips at a set ankle when they tend to turn in



Body brace or corset

for curve of the spine



Body brace with leg braces

for body and back weakness together with hip and leg weakness



Different materials and ways to make braces

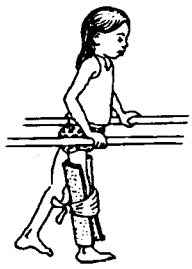
As we discussed in Chapter 57, **an ideal brace should:**

- serve its purpose well (help the child walk or function better)
- be comfortable
- be lightweight yet strong
- be as attractive as possible
- be easy to put on and take off
- do no harm
- be low cost
- be easy and quick to make with local tools and limited skills
- use local or easily available materials
- be easy to repair and adjust as the child grows or develops
- be long lasting

Unfortunately, no brace will meet all these requirements. As much as possible, **try to put the child's needs first.**

In this chapter we give ideas for making different braces using various materials. When deciding how to make a brace, carefully evaluate both the child's needs and the available resources (see Chapter 57).

Sometimes it is wise to start with a simple low-cost temporary brace or splint to see how well it works and what the problems are.



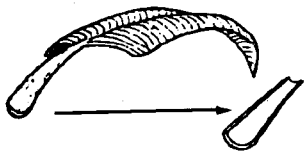
Keep old and outgrown braces for testing on new children before final braces are made.

But take care not to discourage the child by making him use braces that do not fit him well.

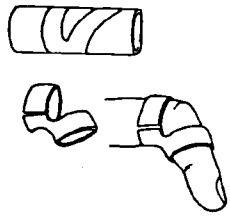


Examples of very simple, low-cost braces and splints:

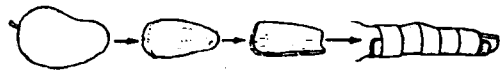
A temporary leg splint of cardboard, folded paper, or the thick curved stem of a dried banana leaf, or palm leaf.



Aluminium tube finger splint



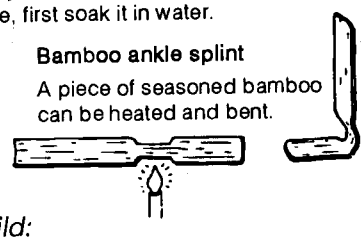
Mango seed finger splint



Remove the woody coat of a mango seed, and wrap the coat firmly onto the finger. It will dry into a firm splint. To change its shape, first soak it in water.

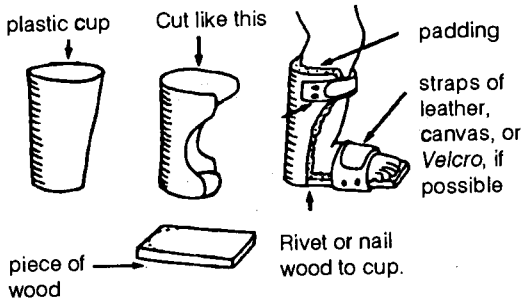
Bamboo ankle splint

A piece of seasoned bamboo can be heated and bent.

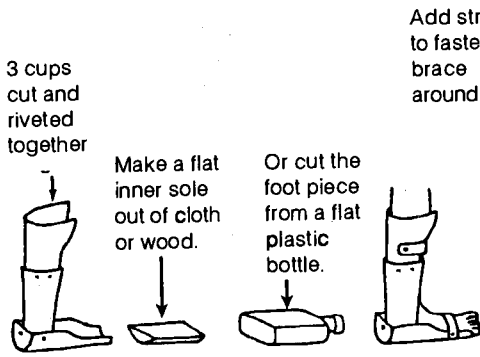


Plastic cup ankle braces for night or temporary use on a small child.

For a small baby:



For a child:



Metal or plastic braces

Modern, high-quality braces are usually made out of metal or molded plastic.

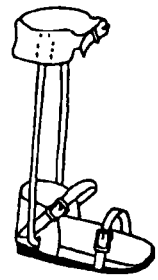
The best metal is a mix or 'alloy' of aluminum and steel which is both light and strong. However, this is very costly and often hard to get. Pure aluminum is very light, but breaks easily, especially when you try to bend it. Steel is cheaper and easier to bend and weld, but is much heavier.

The best plastic for braces is probably polypropylene, which is strong, light, and fairly easy to shape when hot.



plastic below-knee brace

Pre-formed metal parts for making these braces are sold at ***orthopedic*** supply stores. Unfortunately, they are usually much too expensive for a community program. However, sometimes you can get large orthopedic centers to donate old braces, from which locking knee joints and other pieces can be used to build high-quality metal or plastic braces. Also, many broken or outgrown braces are lying in the corners of thousands of homes. A campaign to get families to donate these can greatly reduce the costs of making high-quality braces.



metal below-knee brace with wood *clog*

Low-cost metal or plastic braces can be made in a village shop. They can be made simply, with or without joints. Since children grow quickly, they often need a larger brace every 3 to 6 months. Therefore, keeping cost low and work simple is essential. (See Chapter 57, p. 639.)

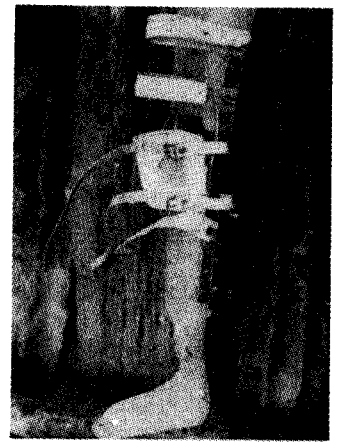
Metal and plastic braces each have advantages and disadvantages. We discuss these on p. 662 and 670.

In Mexico, we have found that for most children who need below-knee braces, plastic works best. And the children (and parents) like it more.

However, a child with a lot of muscle tightness (due to *spasticity* or contractures) which pulls his foot a lot to one side, like this,

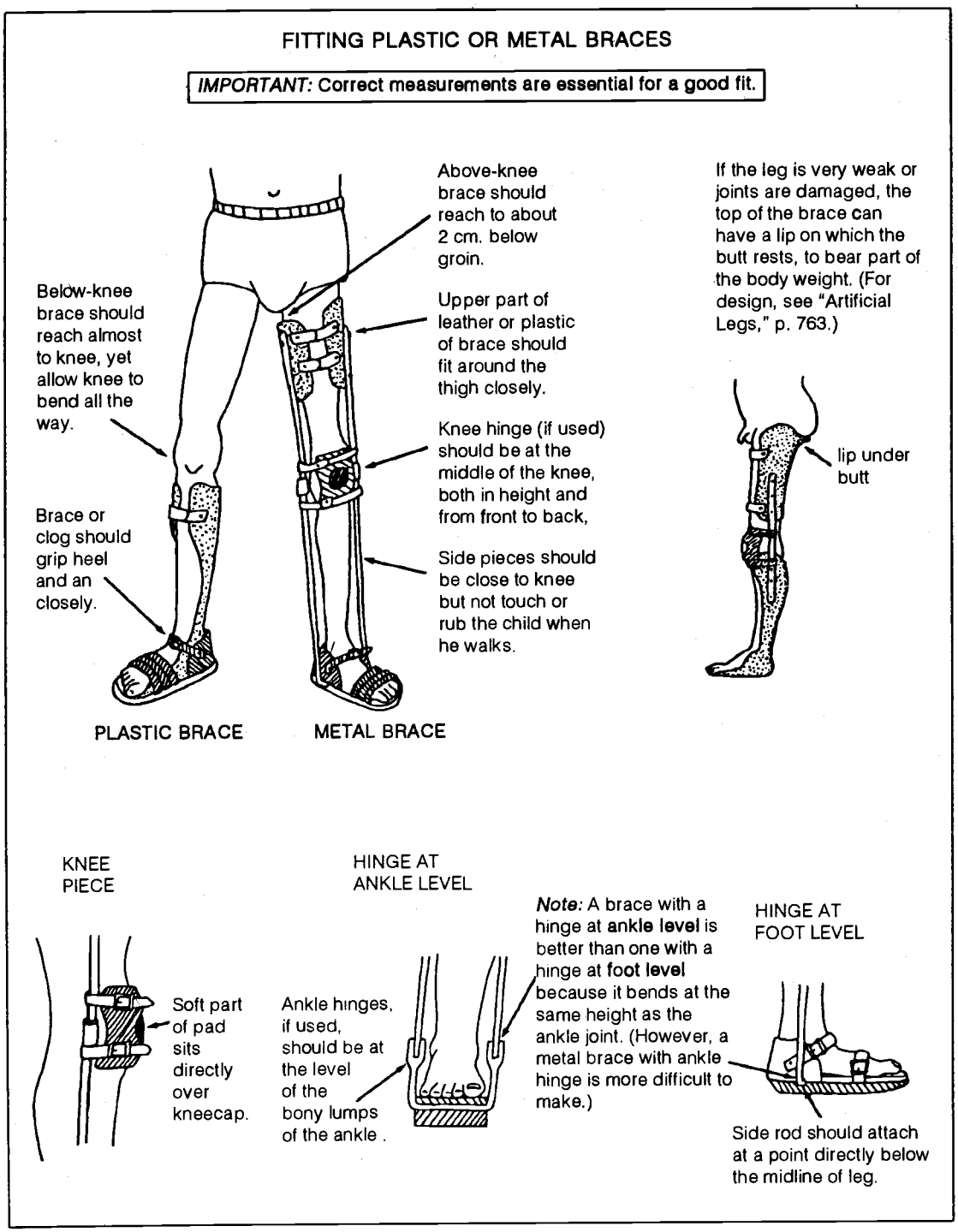


may need a metal brace with an ankle strap. After the brace is on, the strap is tightened to pull the foot into a better position.



Above-knee braces can be made using a combination of plastic and metal.

Whenever possible, equip your village shop to make both plastic and metal braces. That way, you can make what seems most appropriate for each child.

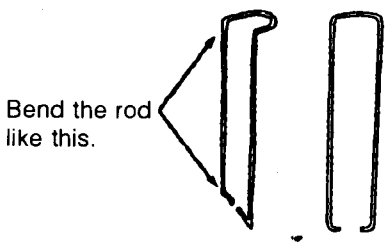


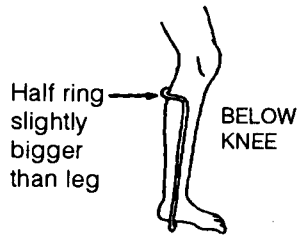
METAL BRACES

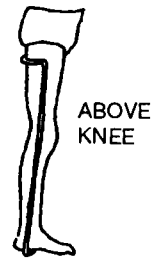
The advantages of simple metal braces are that they are quick, easy, and cheap to make. They often last longer, and, if used with sandals or clogs, in hot weather they are cooler than plastic. However, they also have **disadvantages:** because a shoe, sandal, or wood 'clog' must be built or attached to the brace, there is additional work and cost. Also, they are heavy, clumsy, and more noticeable. In hot or wet weather, leather or cloth, or even the metal starts to rot. Shoes or boots which the child cannot change, even when they get wet, begin to stink.

METAL ROD BRACES* using 're-bar' (reinforcing rod for use in cement building construction).

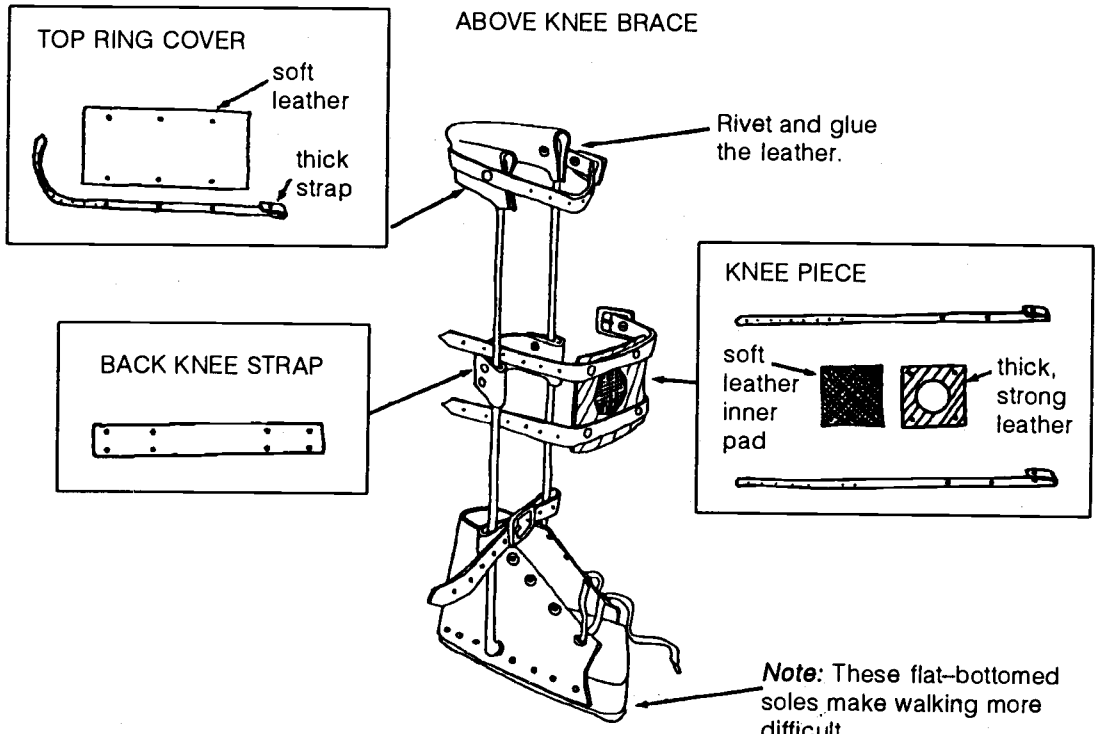
For a brace shorter than 50 cm. (20 inches) you can use rod that is 5 mm. thick. For a longer brace, the rod should be thicker—up to 8 mm.



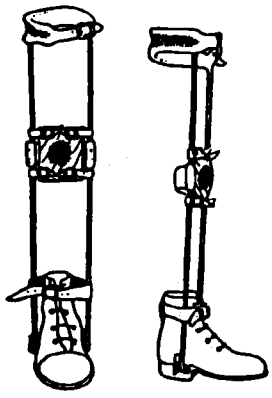




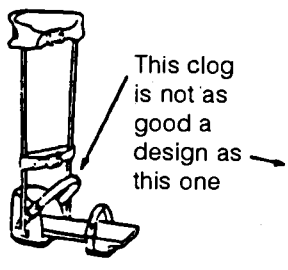
ABOVE KNEE BRACE

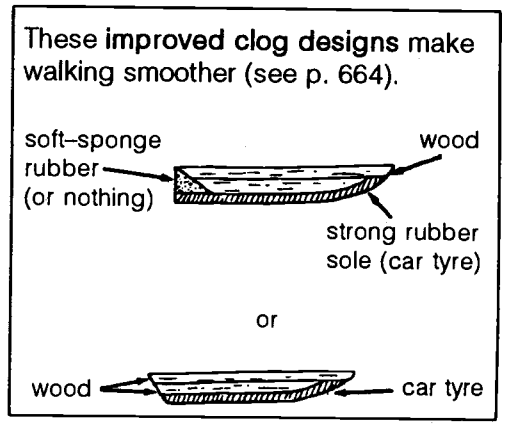


ABOVE-KNEE BRACES



BELOW-KNEE BRACES





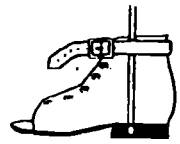
* Much of the information on metal braces, on this and the following pages, is taken or adapted from *Poliomyelitis* by Huckstep, in *Simple Orthopaedic Aids* by Chris Dartnell. For complete references, see p. 769 and 774.

SHOES AND CLOGS FOR METAL BRACES

High-top leather shoes often work best, especially in communities where children usually wear shoes.



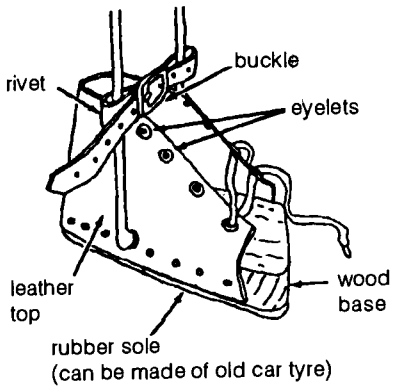


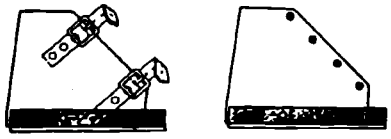


Leaving the toes open to 'breathe' is also important if a child is not likely to wear (or wash) stockings.

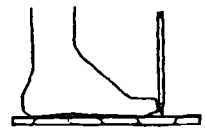
For adding thicker soles and making other changes, it helps to buy shoes **with soles that are sewed on.** (Today, many shoes have plastic or rubber soles that are glued on or molded with the shoe. These are much harder to work with.)

Unfortunately, leather shoes are costly. Also, they may not last long in rain and mud. So, you may want to make simple, low-cost wooden-soled shoes, or clogs. This design is from *Simple Orthopaedic Aids*, which gives complete instructions (see p. 774).



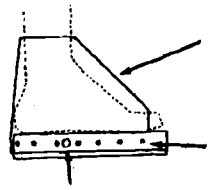


1. Draw around the foot on a piece of wood about 2 1/2 cm. thick. Be sure to use a wood that is not likely to split.



2. Leave extra space as shown (to allow for child's growth). Cut out the piece of wood.



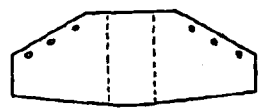


3. Carefully draw this shape on a piece of paper, using the length of the clog as a guide. Then cut it out.

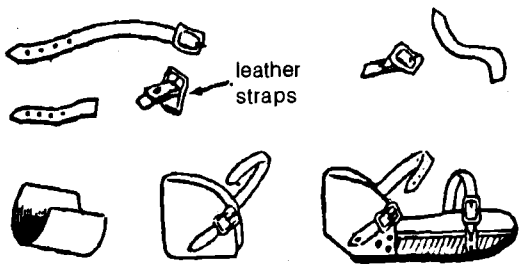
Put nails here.

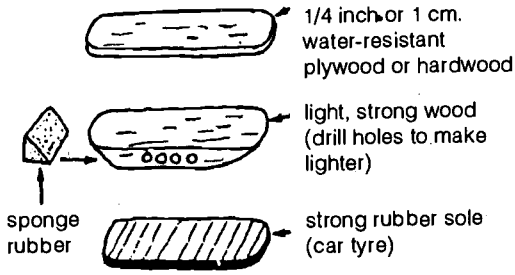
Drill hole for brace. 1/3 of the way up clog.

4. Now draw both sides of the leather top. Between the 2 sides add the width of the clog.



In communities where most children go barefoot, a disabled child may prefer more open clogs. This design is adapted from Huckstep's ***Poliomyelitis,*** and the 'Jaipur Sandal'.





Note: These open clogs are hard to fit on deformed feet or feet with tiptoe contractures. In such cases, high-top clogs or boots work better. Or use plastic braces molded to fit the foot.

HOW TO CONTROL UP AND DOWN MOVEMENT OF FOOT

CONTROLLING FOOTDROP AND TIPTOE DEFORMITIES

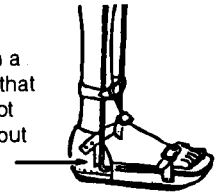
A child with 'footdrop' or a floppy foot that hangs down so that she has to lift her leg high with each step.



needs a brace that holds the foot up. Use a plastic brace.

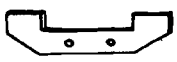


or a metal brace with a backstop that lets the foot bend up, but not down.

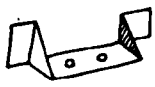


Making a backstop

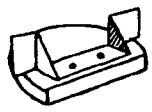
Cut a thin plate of steel



Bend it

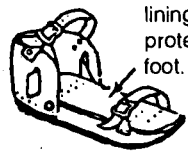


Screw it to the heel piece

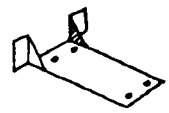


Assemble clog

Put in a lining to protect foot.



Note: A child with spasticity whose foot pushes down hard may need a longer plate to keep it from working loose.

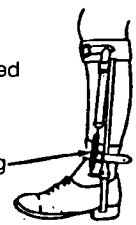


Toe-raising spring

Another way to help prevent footdrop is with a toe-raising spring.

This is a more complicated design.

wire spring



This is a simpler design.

piece of car tyre inner tube



CONTROLLING FOOT-RISE AND UNWANTED KNEE-BEND

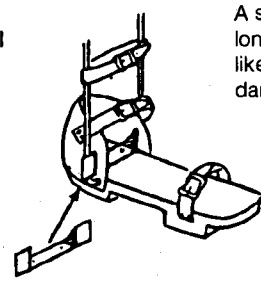
A child who walks with knees bent and feet bent up.



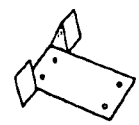
may (or may not) be helped by a brace that prevents the toot from bending up as much It possible, use a stiff **plastic brace.**



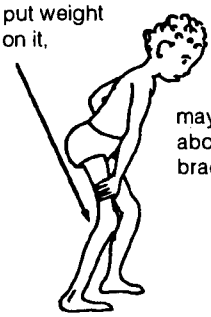
Or use a **metal brace with a stop** placed in front of the upright bars



A strong stop with a long plate will be less likely to work loose or damage the clog.



A child whose weak leg bends at the knee when he tries to put weight on it,

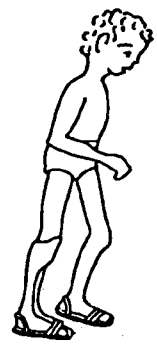


may need an above-knee brace.

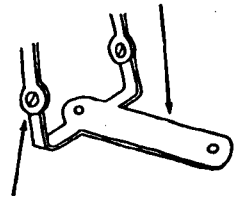


But sometimes a **below-knee brace** that stops the foot from bending will help push the knee back enough so that the child can support his weight on it (See p. 677).

The brace can be of stiff plastic. or metal with stops to prevent foot-rise.



If a brace with an ankle joint is used to prevent the ankle from bending up, the base piece will need a long. strong, forward plate



The joint can be adjusted to allow only the desired range of motion

KNEE HINGES

Braces with locking knee hinges permit the child to bend her knees for sitting or squatting.

Non-bending knees are satisfactory for most children. The child can sit with her leg straight.

NON-HINGED BRACE



However, in some communities, a child may 'fit in' better if he can squat.

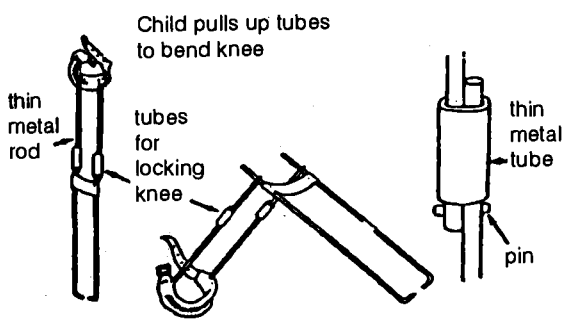
However, hinged braces have disadvantages: they are more costly and take longer to make. A child outgrows them quickly—unless they are adjustable. So use your judgement.

HINGED BRACE

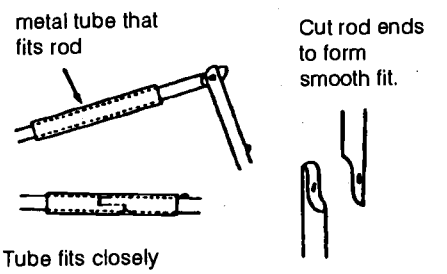


The knee hinge locks for walking and unlocks for sitting or squatting.

Hinges on a round-rod brace

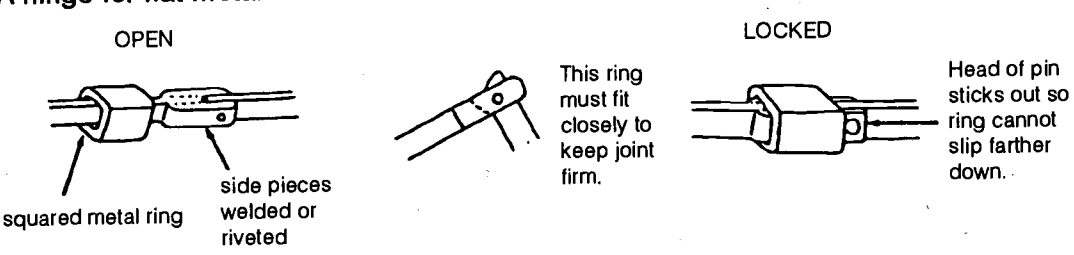


A BETTER HINGE



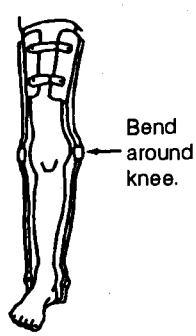
A simpler hinge such as the ones above for a round rod can also be used on a flat rod.

A hinge for flat metal bar



BRACES THAT FOLLOW THE SHAPE OF THE LEG

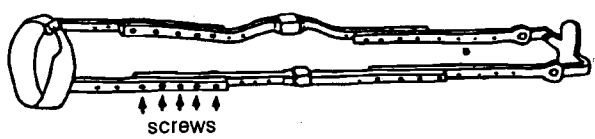
Flat metal bar can be bent to fit the shape of the leg more closely. This is not always necessary but if done well the brace will fit better - especially when the bar is used with moulded plastic.



Instructions for bending and fitting the rod are on p. 677.

ADJUSTABLE BRACES

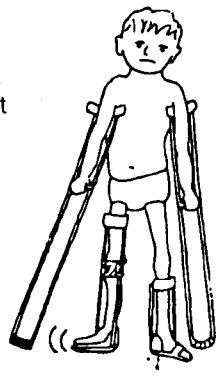
As the child grows, a brace made like this can be lengthened. Teach family members how to do this.



HIP BANDS

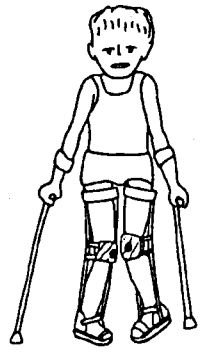
Braces with a hip band may be needed for the child:

whose leg (or legs) is so weak at the hip that it flops or turns far out to one side.

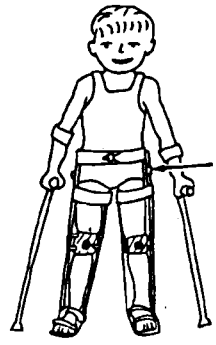


WITHOUT HIP BAND

or whose legs tend to twist too much inward (or outward).



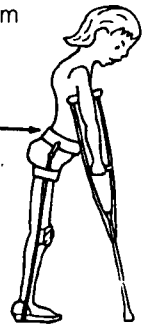
WITHOUT HIP BAND



Put hinges at height of hip bone.

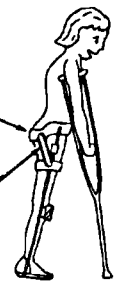
WITH HIP BAND

A common problem with hip bands is that the low back bends forward and the buttock sticks out. This can cause back problems, and hip contractures.

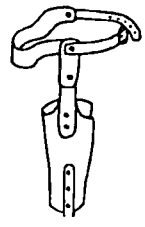


A hip band that dips down in back to push in the buttock helps prevent this problem.

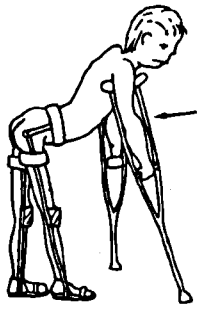
If necessary, add an elastic strap here.



The back of the hip band can be made of thin metal lined with leather, or of strong plastic.

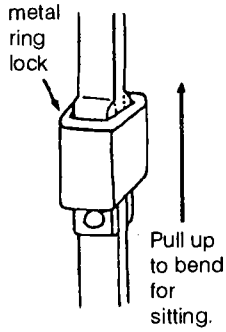


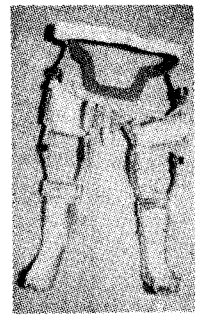
On plastic braces the side bars and hinges can also be made of thick, strong plastic. This adds some flexibility, which will be better for some children but not provide enough support for others.



A child who tends to flop forward at the hips, may need a hip band with a locking hinge. You can use the design on p. 666.

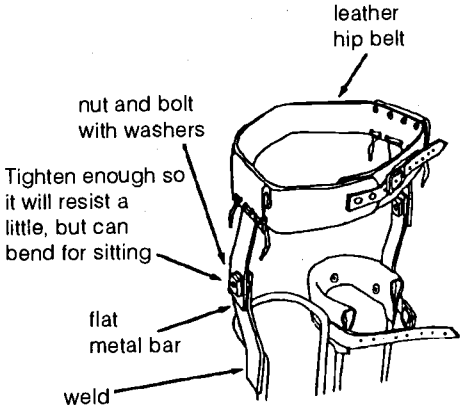




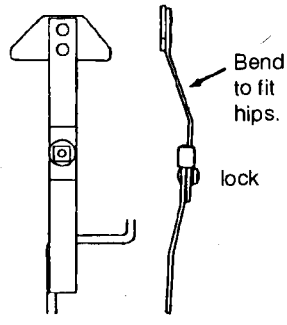


Braces with plastic hip band and locking plastic hip hinges. (PROJIMO)

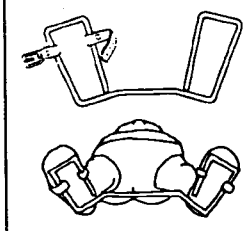
Hip band without lock



Hip band with lock



For a young child whose feet turn in a lot, **a night brace to hold the feet (and hips) turned outward** may help. It can be made from a thin metal bar or from wood.

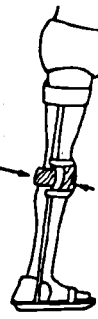


KNEE PIECES (Use the design on p. 663.)

A child with a weak leg that straightens normally,



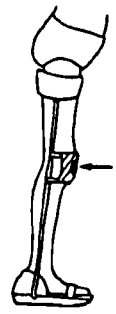
needs a slightly loose strap behind the knee,



and a firm, comfortable knee piece.

A child with a leg that does not quite straighten.





needs a knee piece that firmly pulls the knee back.

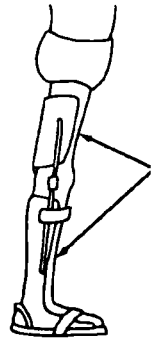
A child with a knee that bends backward,



needs a firm strap behind the knee that lets the knee go back only a little.

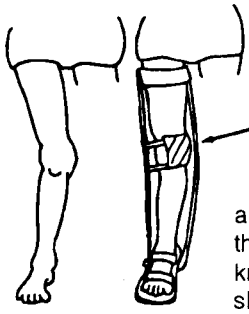


(A front strap may also be needed.)



For children with a severe back–knee problem, it is often better to use a plastic brace that distributes pressure over a wide area above and below the knee. (This is more comfortable than a behind–the–knee strap that presses only on a small area.)

A leg that bends in at the knee,

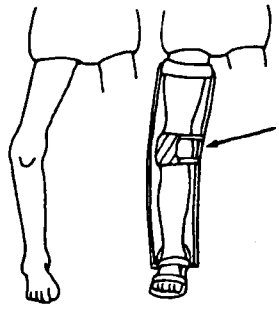


needs a knee piece that pulls the knee outward,



and also one that pulls the knee back (as shown above).

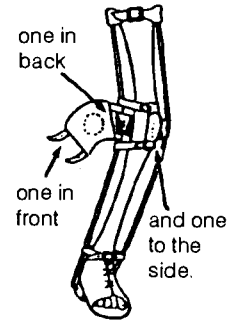
A leg that bends out at the knee.



needs a knee piece that pulls the knee inward,

and also one that pulls the knee back.

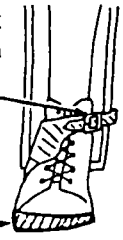
When necessary, you can use 3 knee pieces:



ANKLE STRAPS



For an ankle that bends out, use a strap that pulls the ankle in.



A sole raised on the outer side may also help

Shape of ankle strap





For an ankle that bends in, use a strap that pulls the ankle out.



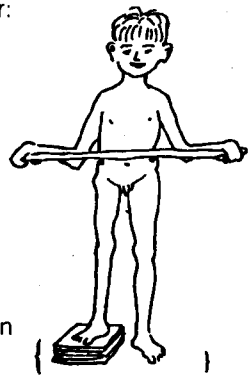
A sole raised on the inner side may also help.

RAISED SOLES OR 'LIFTS' for one leg that is shorter

(For instructions on measuring leg length difference and for homemade measuring instruments, see p. 36.)

For a child who has one leg shorter than the other:

Measure the difference in leg length.



Make the 'lift' of the sole about 1 cm. shorter than the difference in leg length.

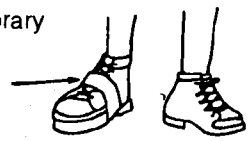
difference in leg length

amount of lift needed

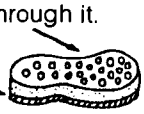
> ***Note:*** Almost all children have one leg that is a little shorter than the other, and this does not usually affect how they walk. Raised soles ('lifts') are usually not needed if the difference in leg length is less that 2 cm.
>
> However, a child who drags a foot because his hips tilt down on that side may be helped by a small lift on the other side–even if that leg is the same length or longer. (See p. 183.)

IMPORTANT: Before putting a permanent lift on a shoe or sandal, test it by tying or taping on a **temporary lift**. Watch the child walk and ask how he likes it. You may want to try several heights before deciding on the one that works best.

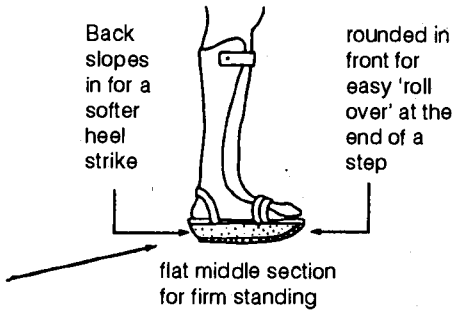
Tie on a temporary lift with string, tape, or a loop of inner tube.

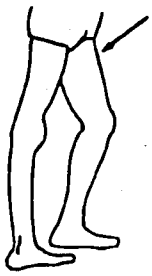


Material used for lifts should be as lightweight as possible. You can use cork or a light, porous rubber. If the material is heavy but strong, to make it lighter you can drill holes through it. Put a thin, strong sole on the bottom.

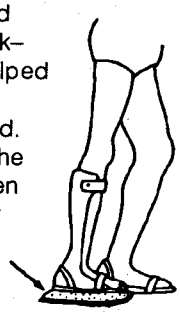


For a lift with a stiff-ankle brace, the child can often walk more smoothly with a 'rocker bottom' sole.



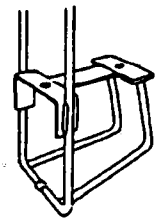


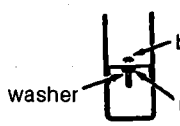
A child with a mild to moderate 'back–knee', may be helped by a heel that extends backward. This helps push the knee forward when the child puts her weight on foot.

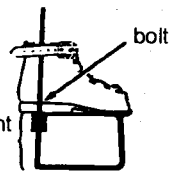


For a more severe back-knee, the child may need a long-leg brace (See p. 73 and 668.)

A high lift, when needed, can be built into a bar brace.







Design from *Simple Orthopaedic Aids*, by Dartnell.

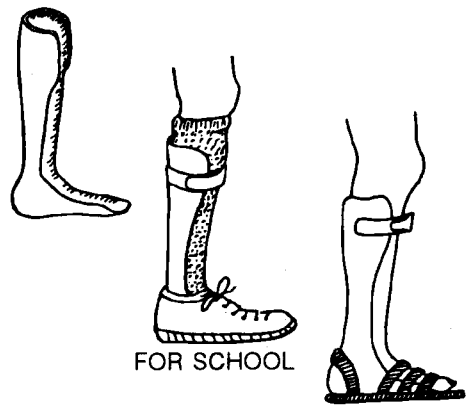
Ask a local shoe or sandal maker to teach you how to fasten on the soles and lifts.

PLASTIC BRACES

Below the knee

For most children who need a below-knee brace, plastic braces molded to fit the leg and foot of the individual child have many advantages:

- They are lightweight and often more comfortable than metal braces.
- They fit the child comfortably and exactly (if made well).
- They can be worn with ordinary shoes or sandals, which can be easily changed when they get worn out or wet. Shoes can be changed for school and for work.
- They are water resistant and easy to clean.
- They are less noticeable than metal braces. If desired, socks can be worn over them to hide them.
- Children usually prefer them and are more likely to keep wearing them.



Although a little more equipment and skill are needed to made plastic braces, once a village worker has learned the basic technique, they can be made as quickly and easily as a simple metal brace with a clog.

A **disadvantage** to plastic braces is that usually after a year or two the plastic 'gets tired' and breaks. However, growing children need larger braces fairly often. It is wise to **keep the plaster mold of each child's brace so that a new brace can be easily made if needed.**

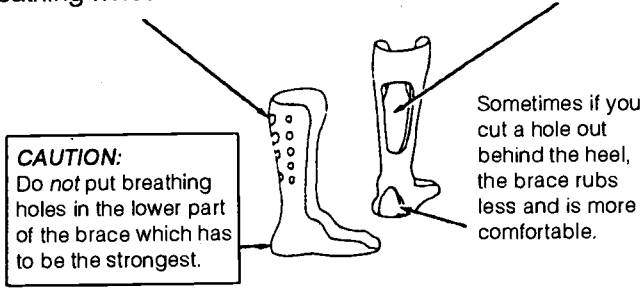
A suggestion to save time and money:



Keep the mold of the child's foot– or have the family keep it.

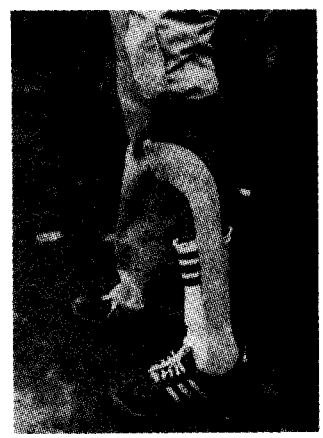
The biggest expense in making plastic braces is the plaster bandage used for casting a mold of the leg. The cost can be reduced a lot by making your own plaster bandage material (see p. 693).

Plastic braces can feel uncomfortable in hot weather and can lead to skin irritation and fungus ***infections*** if care is not taken. They can be made cooler by drilling 'breathing holes' in them. Or cut out a hole in the back.



CAUTION:
Do *not* put breathing holes in the lower part of the brace which has to be the strongest.

Sometimes if you cut a hole out behind the heel, the brace rubs less and is more comfortable.



This design of plastic brace supports the knee from the front and pushes it back (see p. 665 and 677).

To prevent skin irritation, it is important to bathe daily. It also helps to wear cotton (not nylon) stockings under the brace and to use clean stockings every day.

How to make plastic braces

Here we describe 2 methods for making molded plastic braces:

The first method uses **old plastic buckets** or containers, and needs less equipment. Unfortunately, these braces tend to break easily when used for walking. However, they make excellent, low-cost **night braces** (to wear while sleeping).

The second method uses sheets of polypropylene plastic. Additional equipment (such as a vacuum sweeper) is needed, and it is a little more expensive. However, the result is a high-quality brace that can last for months or sometimes years.

Method 1: Plastic bucket braces

Equipment and materials needed:

- **'stockinette', old stocking** or **thin cloth strips** (for wrapping leg before casting)



- **plaster bandage** rolls for plaster casts. (To reduce costs, roll your own. See p. 693.)



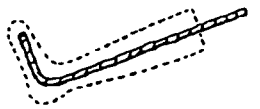
- a **sharp knife** or single-edged razor blade



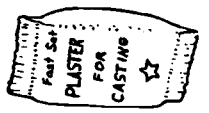
- a piece of **soft rope** about 1/2 meter long



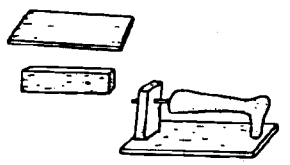
- a piece of old **reinforcing rod**, pipe, or iron, bent to fit inside the foot cast



- fast-setting **building plaster** for the solid plaster mold



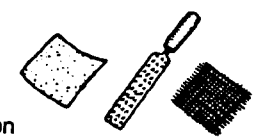
- 2 pieces of wood nailed together to form **a rack** to hold cast in this position



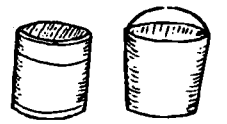
- several **long rubber strips** cut from car tyre tubes



- tools for smoothing plaster and plastic: **file or rasp**, piece of **broken glass**, piece of **wire screen**



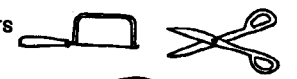
- **large plastic bucket** or containers to be cut up. Plastic should be at least 2.5 mm. thick and of flexible (not brittle) plastic



- **other buckets or water containers**



- **saw or strong scissors** for cutting plastic



- an **oven** (wood, gas, or electric)



- large metal **cooking tray** or sheet of metal



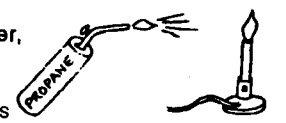
- thick **gloves** or potholders



- small **soldering iron**



- if possible, a **gas burner, torch**, or '**heat gun**' to 'spot heat' the plastic (*Note:* A hair dryer does not give enough heat.)



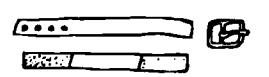
- **drill** and **bits**



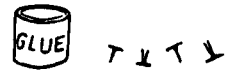
hand or electric



- **strap and buckle** or *Velcro* (plastic straps, one with barbs and the other with hairs so that they stick to each other)



- **glue or rivets** or both



Making the plastic-bucket brace consists of 3 main steps:

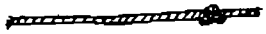
A. Making a hollow plaster cast of the child's leg

B. Making a solid plaster mold of the leg

C. Heat–molding the plastic–bucket brace

A. Making the hollow cast

1. The knot in the end of a soft rope.



2. Put the rope on top of the leg with the knot between the toes.



3. Put the stocking tightly on the foot with the rope inside (or wrap it with a thin cloth). Avoid wrinkles.

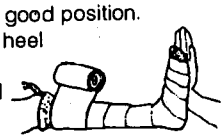
Make sure the rope stays very **straight**.



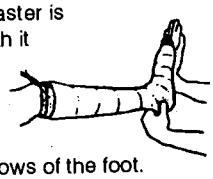
4. Wet a plaster bandage and squeeze out the extra water.



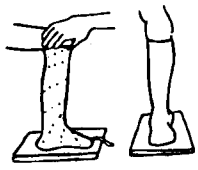
5. Wrap on a thin cast (about 3 layers) while someone else holds the foot in a good position. Be sure the heel is covered with several layers.



6. While the plaster is still wet, smooth it gently with moist hands, and press the cast gently into all the hollows of the foot.

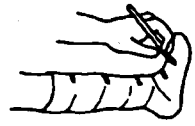


7. Before the plaster becomes firm, place the foot in exactly the position that you want the brace to hold it in. Sometimes it works well to hold the foot in your hands. But often it works best to have the child step firmly on the floor, or on a padded board.



Be sure to position the leg **straight** up, from side view and front view.

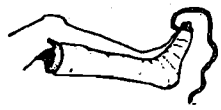
8. Draw some lines over the front of the cast.



9. When the cast is almost firm but still damp (usually in 5 to 10 minutes), carefully cut through the plaster over rope. Take care not to cut the child.



10. Then gently remove the cast without changing its shape.



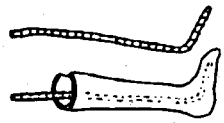
11. Quickly (before it is fully hard) close the cast, line up the lines you drew, and tie it shut with cloth or string.

12. Tie a cloth tightly over the opening of the toes.

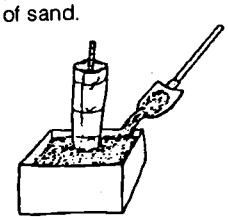


B. Making the solid plaster mould

1. Put a bent piece of rod into the hollow cast.



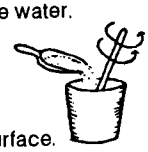
2. Hold the cast in a standing position–perhaps in a box of sand.



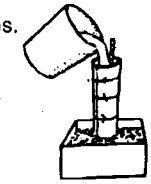
3. Mix the plaster: Put water in a container, enough to fill the cast.



While stirring, sprinkle dry plaster into the water. Keep adding until the mix is just thick enough that wrinkles stay a moment on the surface.



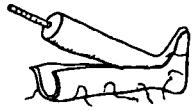
4. Quickly pour the mix into the cast. Jiggle the rod and tap the cast to be sure the mix fills all spaces.



5. Hold the rod in the middle until the plaster is firm.



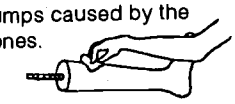
6. After plaster hardens fully (about one hour) remove the solid mold.



7. Being careful not to change the shape or size of the mold, use fresh plaster to fill in any holes or pits that are not caused by the shape of the foot. Add a little fresh plaster over bony places (so final brace will not rub).



8. Smooth the surface (with a file, piece of wire screen, or piece of broken glass). Do *not* reduce any of the bumps caused by the bones.



C. Heat–molding the plastic–bucket brace

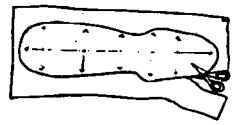
1. Mark on the child's leg the shape of the brace.



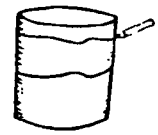
2. Take measurements as shown for the width and length of the brace.



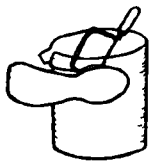
3. Draw an outline on paper, according to the measurements and cut out the pattern.



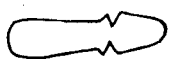
4. Mark the pattern on the plastic.



5. Cut out the pattern with a saw or strong scissors.



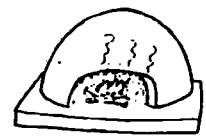
6. Make V-shaped cuts here to help bend the hot plastic around heel.



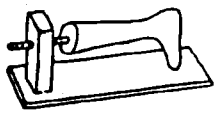
7. Heat the oven to at least 450° F (230° C). If you cannot measure or control heat, put a small piece of plastic into the oven and heat it until the plastic becomes soft and gooey.



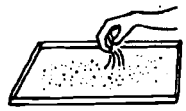
8. Heat the plaster leg cast in the hot oven for 15 to 20 minutes.



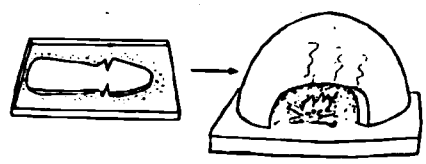
9. Put the hot mold on the rack.



10. Lightly sprinkle dry plaster or talc on a metal sheet or tray.

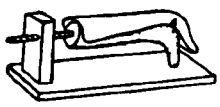


11. Put the plastic form on tray and put the tray into the hot oven.

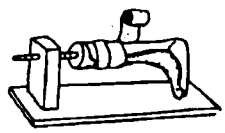


12. Leave it in oven only until plastic becomes somewhat flexible.

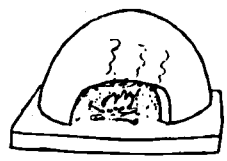
13. Take hot plastic out of oven with gloves. Bend it over the hot mold.



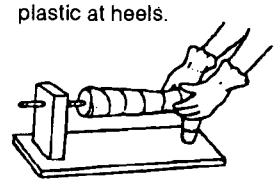
14. With strips of rubber, wrap plastic tightly to force it against the mold.



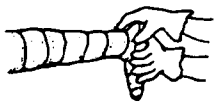
15. And put it back into oven until plastic gets softer.



16. Remove from hot oven and press forcefully (with gloves) to fuse overlapped plastic at heels.

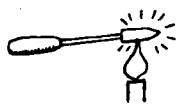


17. Also press in any hollows around bones and on bottom of foot. Keep pressing until plastic begins to cool and stiffen.

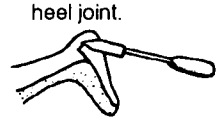


18. While brace is cooling, heat soldering iron.

Heat to moderate heat–*not* red hot.



19. Unwrap cloth from brace while still warm and use soldering iron to smooth and weld heel joint.

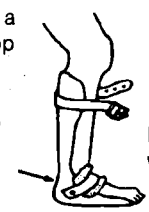


20. When cool, trim and smooth the edges of the brace.



21. Glue or rivet a strap near the top of the brace.

For night splints, add 1 or 2 more straps at the ankle and foot.

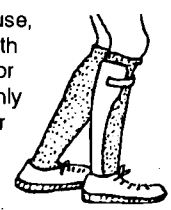


Pad well.

For easier fastening, use *Velcro* straps.



For day use, or use with sandals or shoes, only the upper strap is needed.



Note: Braces made from plastic buckets or containers tend to break fairly easily if a larger child uses them for walking. It is better to use polypropylene plastic (see next page).

Take care not to overheat the plastic, because the plastic used for many buckets and containers tends to wrinkle like bacon when it gets too hot.

Method 2: Polypropylene braces

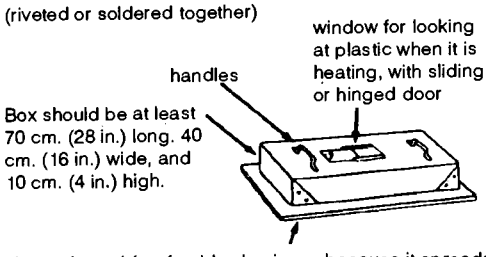
Polypropylene is a special plastic available in large sheets from orthopedic supply stores and some plastic factories. For most braces, sheets 30 cm. by 60 cm. (1 foot by 2 feet) are large enough. Thickness should be 3 mm. (1/8 inch) for thinner, more flexible braces and 4 mm. to 5 mm. (3/16 inch) for stronger, less flexible braces.

> ***Polypropylene***, where available, is usually the best plastic for braces. It is flexible but strong. It is easy to stretch and mold when hot. Cost is US $2.00 per brace. ***Polyethylene*** can also be used but is more likely to wrinkle like bacon if it gets too hot. You can experiment with whatever plastic you find. A program in Pakistan uses **plastic bus windows**, although this hard clear plastic (***Plexiglas***) is more difficult to stretch and shape when hot.

This method is the one used by professional brace makers. Here we simplify it as much as possible. Equipment and materials needed are mostly the same as in Method 1 (see p 671). However, high-quality braces can be made more easily with a few extra pieces of equipment (they are not absolutely necessary). This **extra equipment** includes:

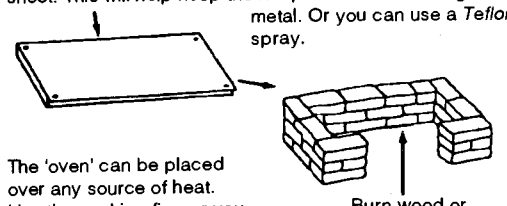
• special oven*

SIMPLE SHEET-METAL BOX OVEN
(riveted or soldered together)



sheet of metal (preferably aluminum, because it spreads heat best) at least 6 mm. (1/4 in. to 1/2 in.) thick

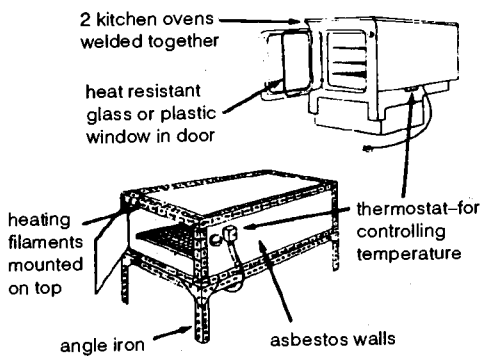
If you can get it, rivet a piece of *'Teflon'* cloth over the metal sheet. This will help keep the hot plastic from sticking to the metal. Or you can use a *Teflon* spray.



The 'oven' can be placed over any source of heat. Use the cooking fire, or you may want to build a simple fireplace to support it.

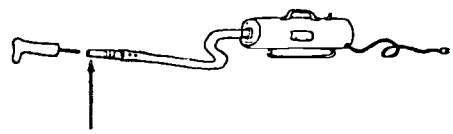
Burn wood or cow dung here.

COMPLEX GAS OR ELECTRIC OVEN
(designs from Huckstep's *Poliomyelitis*, See p. 769.)



• vacuum sweeper

(if electricity is available) or other form of suction. (The suction pulls the hot plastic tightly against the cast until it cools. However, this is not absolutely necessary.)

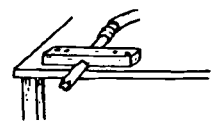


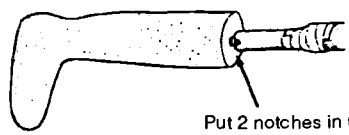
• metal pipe

Tape it to the end of the vacuum sweeper hose.

The pipe should be a little bigger than the rod used in the leg cast. By bending the rod slightly. It will fit very tightly into the pipe.

Figure our some way to clamp or bolt the pipe firmly to a strong bench or table.

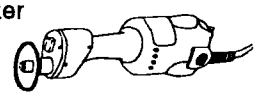




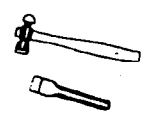
Put 2 notches in the pipe so it will breathe when pushed up against the plaster.

• electric cast-cutter

These are very expensive but a great help if you are making a lot of plastic braces.



If you do not have a cast-cutter you may have to use a hammer and chisel to cut the plastic. You can heat the chisel so that it will melt the plastic.



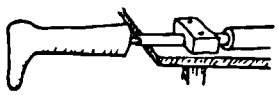
* Some brace makers in Pakistan use no oven, but simply hold the plastic sheet over a 'chula' (earth pot) of hot coals.

Making the polypropylene (or polyethylene) brace

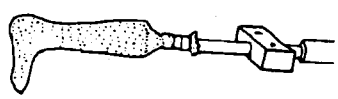
Steps A and B are the same as described for Method 1 (see p. 672).

Step C. Heat–molding the plastic brace

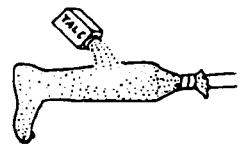
1. Put the rod of the plaster mold into the vacuum pipe. Be sure it is very tight. (If not, take it out and bend the rod a bit more.)



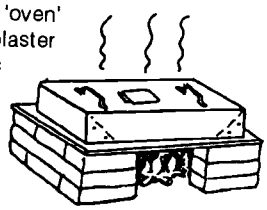
2. Stretch stockinette or stocking tightly over th cast and tape it to the pipe.



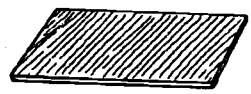
3. Sprinkle dry plaster powder or talc over the entire foot and smooth it with your fingers.



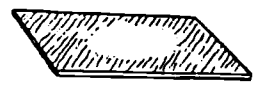
4. Preheat the 'oven' and sprinkle plaster powder or talc evenly over the hot metal sheet.



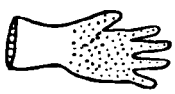
5. Cut a piece of polypropylene plastic large enough to stretch around the entire foot, and put it into the oven to heat.



6. As the plastic gets hot enough to mold, it will turn clear so you can easily see through it. It often gets clear in the middle first.



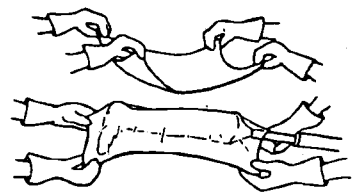
7. To move the hot plastic, 2 persons must wear thick gloves. Sprinkle dry plaster powder, lime, or talc on them.



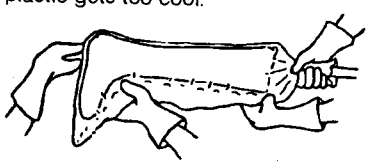
8. As the plastic is getting hot, turn on the suction (vacuum cleaner) and listen for a hissing sound where the pipe joins the cast. (This means the suction is working.)



9. When the plastic is hot enough (clear and limp), remove the oven lid, lift the hot plastic by its 4 corners, and quickly stretch it over the whole cast.

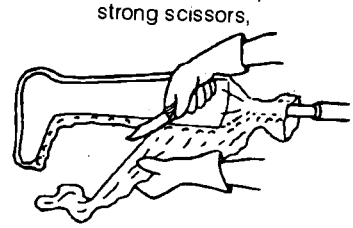


10. Quickly pinch the edges of the plastic together along the bottom side of the leg and around the pipe. Squeeze together all edges to form a seal. You **must work quickly** to complete the seal before the plastic gets too cool.

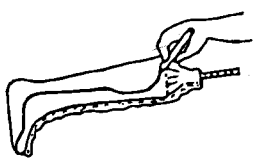


As soon as the seal is complete, the suction should pull the hot plastic close against the cast. But if necessary, help by pushing it into the hollows.*

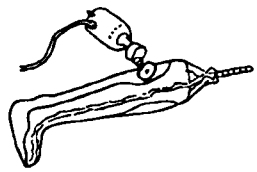
11. While the plastic is still hot and soft, cut off the extra with a sharp knife or strong scissors,



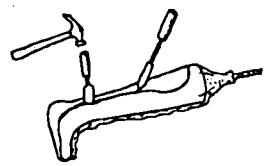
12. After it cools, draw the form of the brace on the plastic,



13. and cut it out either with a cast cutter,



or a hammer and chisel,



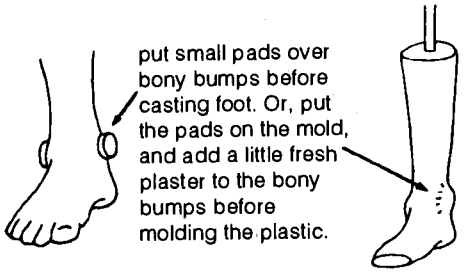
or a red hot soldering iron, or however you can.

Finish the brace in the way described under Method 1 (steps 20 and 21).

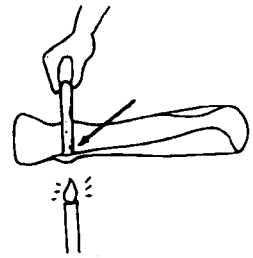
* If no suction equipment is available, you can heat mold the plastic by stretching it over the cast and pushing in the hollows until it cools. With practice, this gives almost as good results, and you only need about half as much plastic.

Making sure plastic braces fit well and are comfortable

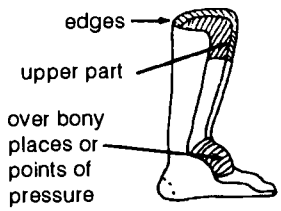
The most common problem with plastic braces is that they **press on bony bumps**. To avoid this,



When the child wears the plastic brace, if it presses too much on bony places, or elsewhere,

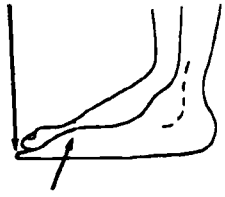


Soft padding inside the brace can make it more comfortable. Places that may need to be padded are:



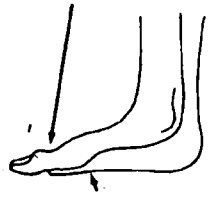
For padding you can use a product called 'moleskin', or a special foam plastic material available from orthopedic supply stores. Or you can glue in pieces of cotton blanket or car inner tube (but make sure the child wears cotton stockings to avoid skin problems).

The sole of the brace can end at the ends of the toes (or slightly beyond to allow for growth).



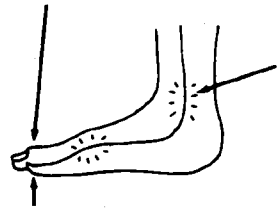
The side of the brace at the foot can extend to the toes if necessary for support.

Or the sole can end at the base of the toes.



For better comfort and shoe fit, the side can dip down around the base of the big toe.

AVOID brace edges that stop at middle of toes.

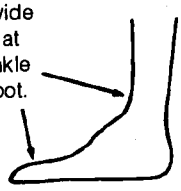


Avoid an edge that curves in (better to heat it and bend it out a little).

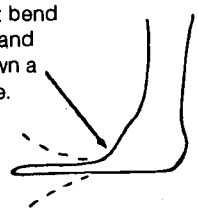
AVOID brace edges that pass across the middle of bony bumps. The edge should be either behind or in front of the bump.

Deciding how wide or narrow to make the sides of the brace at different points will depend on the needs of the particular child.

A child whose ankle or foot is floppy or deformed, or who needs a stiff ankle brace to help push back a weak knee (see p. 677) may need a brace with wide sides at the ankle and foot.

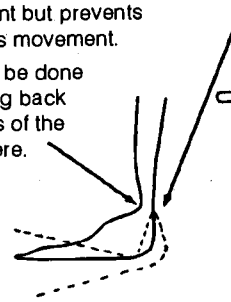


A child who needs only the ankle stabilized may walk better with a brace that lets the front of the foot bend up and down a little.

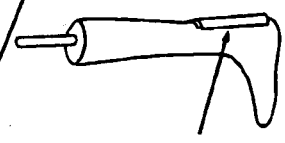


Many children benefit by a brace that allows some up and down ankle movement but prevents sideways movement.

This can be done by cutting back the sides of the brace here.



This will be the weak point in the brace. So, the plastic must be extra thick here.



Or you can strengthen it by putting extra strips of hot plastic on the back of the plaster mold *before* stretching the whole plastic over it.

Different plastic brace models for different needs

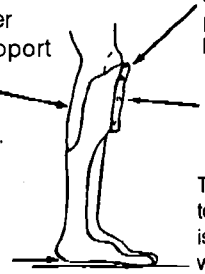
In various places in this book we have shown different brace models and how they meet the particular needs of a child. See, for example, p. 72 to 81 and p. 130. Here are a few more ideas for different plastic braces:

Below-knee brace that gives knee support



The child with a weak upper leg whose knee cannot support her full weight, may be helped enough by a brace that pushes her knee back.

A strong stiff ankle on the brace, with the foot tilted down slightly (more than 90°), pushes the knee back when she steps.



Front of brace presses against knee.

The simplest way to make this brace is to rivet the seam where the plastic joins in front. (See photo, p. 670.)

CAUTION: The shoe or sandal may affect the angle of the foot. Allow for this when deciding the angle for the foot of the brace.



A similar brace can be made in 2 parts.

1. Make the lower part, and place it back on the plaster mold.



2. Place the mold like this and form the top part of the brace over the lower part.

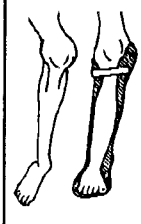
When the child grows, this brace can be made longer by removing the rivets and separating the 2 ends more



rivets

Side-support knee brace

A brace that supports the knee may help a child that has a sideway bend or partial dislocation of the knee.



Make the brace on the side that needs more support.

Also, make the brace higher on the side on the ankle that needs more support.



Also, in an above-knee brace, you can put extra support on the side of the knee that needs it.

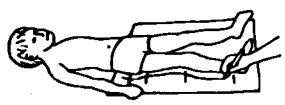
Above-knee plastic braces



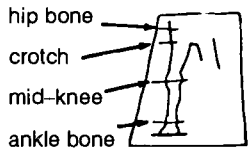
The simplest kind of above-knee plastic brace is a single piece without a knee hinge. You can make it in the same way as a below-knee brace, with or without a footpiece. These braces are useful on small children.

To make a jointed above-knee brace:

1. Draw th shape of the child's leg on paper.



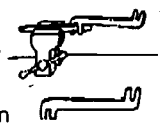
2. Mark the height of the



3. After forming the plastic pieces on plaster molds, bend metal joint pieces so they fit the shape of the leg.



To bend the flat bar, make or buy a bending iron.

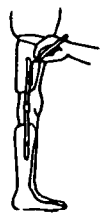


steel bending iron

4. Temporarily pin or bolt the plastic pieces to the metal pieces. Then you can adjust the front-to-back angles with the brace on the child.



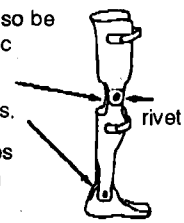
5. When the angles are right, mark the position, and after checking all aspects of fit, rivet the pieces together and add straps and knee supports.



Hinged braces can also be made using the plastic itself for knee hinges,

and even ankle hinges.

However, these hinges may not last long with heavy use.



BODY SUPPORTS

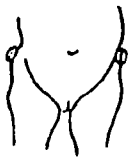


In most cases, a body brace or body jacket probably does little or nothing to correct or prevent further curving of the spine. However, a child with a 'flail' spine that curves so much that it makes sitting difficult or awkward, may sit more comfortably and have more use of her arms if she has a body brace.



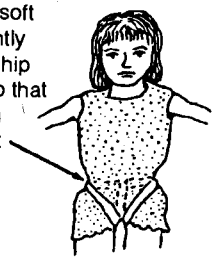
Making a plastic body brace

1. Put small pads over upper outer corners of hip bone.



2. Put a stockinette or old tight-fitting shirt on the child.

Tie a cloth band or soft rope tightly over the hip bones so that it pulls in the waist



3. Cast the child's body with plaster bandage while holding her in a sitting position.

Press plaster into groove here

Bring plaster down to the level of the seat.



While the plaster dries, hold the child as straight as you can.

This 'shell' over the hip bones becomes a base for the final brace to hold her body upright.

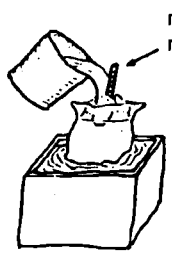
4. Cut the cast into 2 halves and remove.



5. Tape or tie the 2 halves of the cast together and put it into a plastic bag.

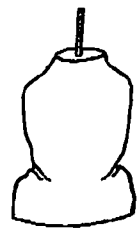


6. Make a solid plaster mold inside the cast (see p. 672).

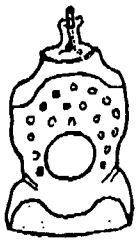


You can make it lighter and save plaster by mixing sawdust or bits of plastic foam into the plaster

7. Remove the plaster mold and smooth it carefully to keep its shape, especially the waist and hip curves.



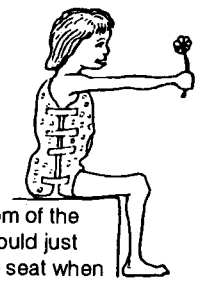
8. Stretch hot plastic over the mold as described on p. 555. If your oven or sheets of plastic are not big enough, you may have to mold it in 2 halves, front and back.



9. Mark and cut the plastic. Leave a little room under arms.

Cut breathing holes and perhaps a large central hole over the stomach.

10. Try it on the child. Make adjustments. Smooth edges. Add padding and straps.



The bottom of the brace should just touch the seat when the child sits.

A body brace attached to leg braces may be needed by a child whose body is weak from the chest down.



* Casting can also be done with the child lying lengthwise over a wide strip of cloth stretched between two points.

BRACES IN INDIA

The Artificial Limb Manufacturing Corporation of India, (ALIMCO) sells metal braces in a kit form to organizations and individuals all over India. The braces are available at concessional rates for people below a certain income group. (For details see section on schemes).

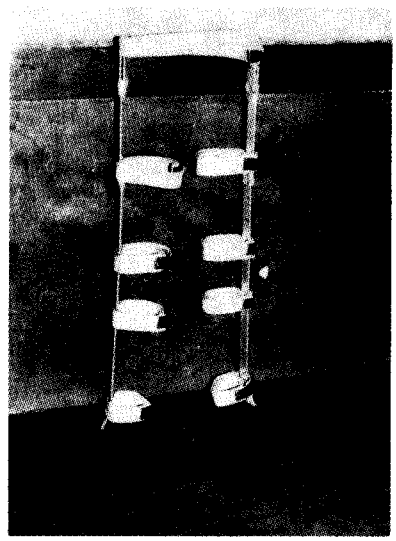
Many voluntary organizations have also have been experimenting at producing cheap and easy to make braces that are culturally acceptable. It has been found that a very large number of children reject their braces.

Some reasons, for this in India are :

- Most children living in villages squat on the floor. The conventional metal brace does not allow a person to squat comfortably so children often end up not wearing them.
- Most children in villages do not wear shoes. Shoes look odd with the traditional dress that girls wear. Many young girls reject the braces for this reason.
- Metal braces have ***not*** been found suitable for disabled children under 8 years of age. There is also an increasing need to produce braces that can be easily replaced and repaired at the village level or within a community. Here are a just few examples of braces that are being developed and tried out at the community level.

SEWA-IN-ACTION (Bangalore)

The braces made by Sewa–In–Action are lightweight, cheap, simple and easy to wear. The brace has just one long metal (aluminium) strip on the lateral (outer) side of the leg The support around the leg (circumference) is given at the back of the knee and above the ankle joint. There is no knee cap. Instead 2 velcro straps are used for strapping. A child can wear simple slippers or canvas shoes with these braces. She can also sit cross legged.



Braces made at Sewa-In-Action



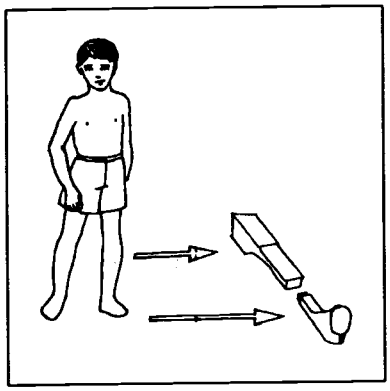
Photo: Sewa-In-Action (Bangalore)

Handicap International

One of Handicap International's main objectives is to help establish small rehabilitation centres and produce simple orthopedic appliances using locally available materials like leather, wood, bamboo, rubber, metal, used tyres etc. The materials used for making braces are:

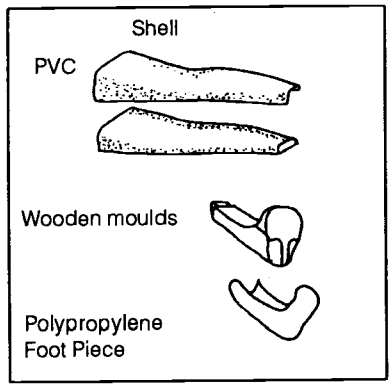
- PVC (polyvinyl chlorine) drain pipes for leg shells.
- Polypropylene sheets for foot pieces.
- Soft iron for hinges
- Ordinary plastic or leather sandals, sports shoes, or even cheaper sandals made of used car tyres and inner tubes are used instead of the conventional shoes.

THE METHOD

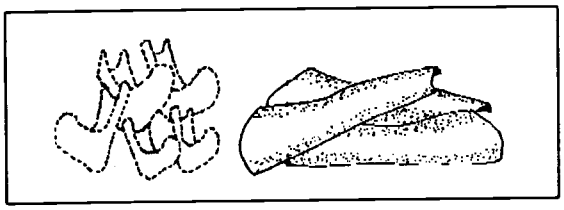


Making wooden moulds

The plastic become soft when heated in an oven and they are then shaped on wooden moulds for the feet or legs. This process is called Drape Moulding

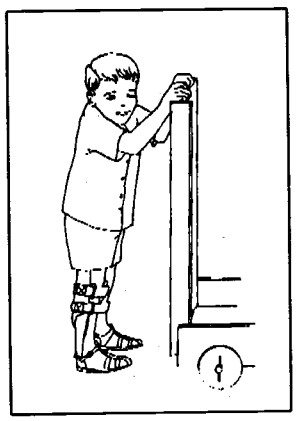


Moulding the shells and foot pieces



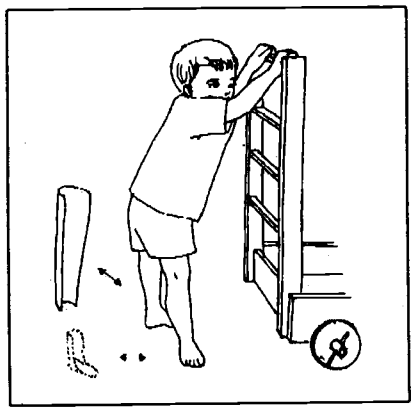
Storage of pieces

Six different standard sizes have been developed which can be adopted to the needs of each child or person. Hence it is possible to have a permanent stock of both leg shells as well as foot pieces.



Finishing the Calipers

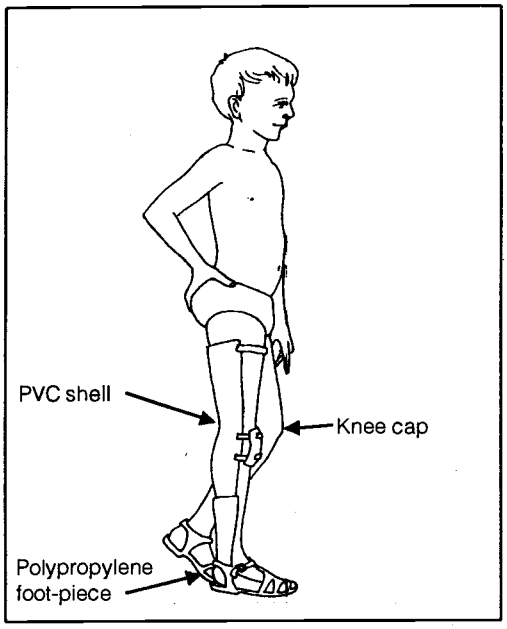
The braces are light weight, washable, strong and can be made within a short period of time. A below knee brace can be made in an hour.



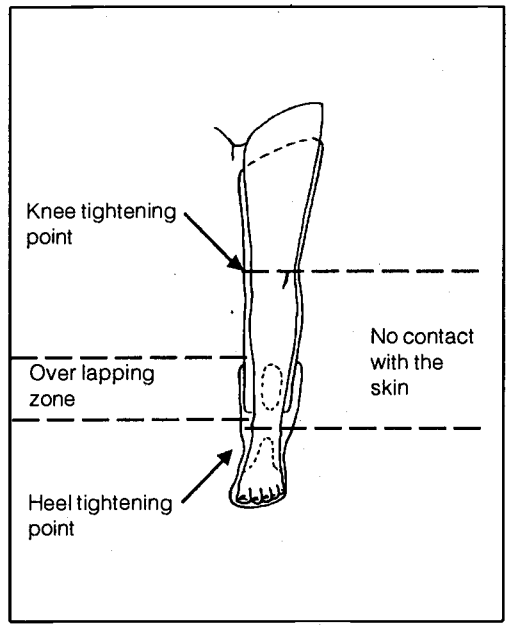
Fitting of Pieces

An above knee (long) brace can be made in half a day. An above knee brace with a hip support will take at the most, two days.

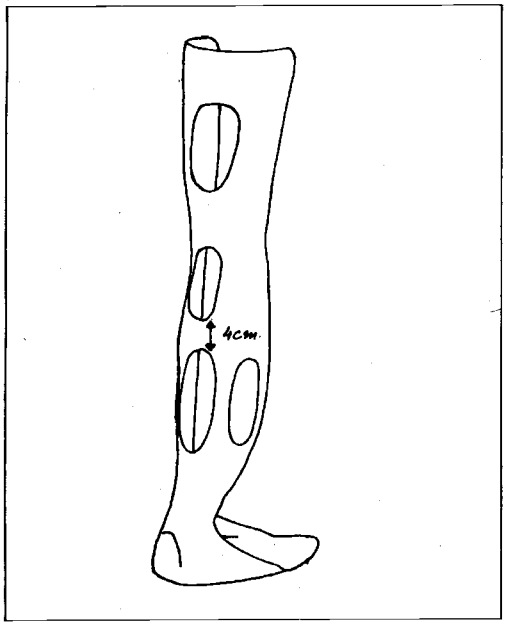
The PVC Long Caliper



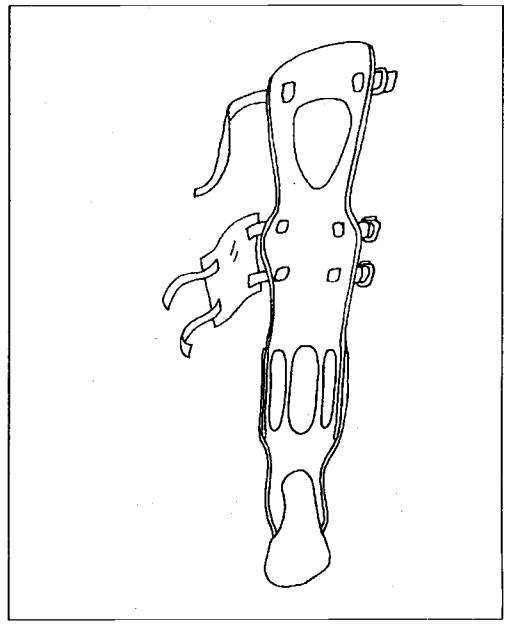
Side view



Front view



Possibility of opening windows



The finished Caliper

The braces are light weight, washable, strong and can be made within a short period of time. A below knee brace can be made in an hour.

An above knee (long) brace can be made in half a day. An above knee brace with a hip support will take ath the most, two days.

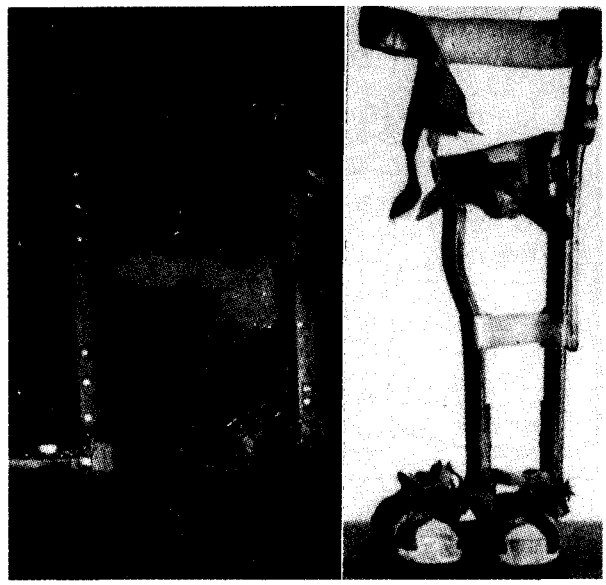
VIKLANG KENDRA

Viklang Kendra at Allahabad specializes in making aids and appliances out of bamboo. It also makes braces out of bamboo. (See p. 654)

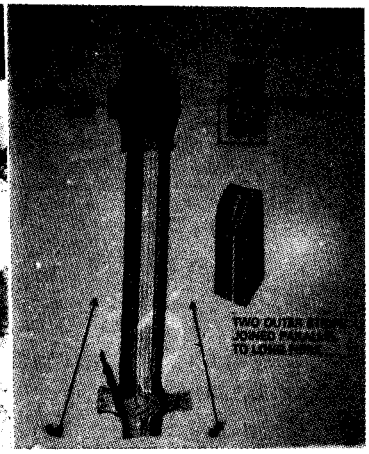
ANKLE FOOT ORTHOSIS

The side bars are made of bamboo pieces that are 1.25 cm thick and 0–6 cm wide. These pieces are attached to wooden clogs by passing a mild steel rod through a hole in the heel. This is attached on either side by welding a flat mild steel disc to the outer aspect of the bamboo pieces.

The calf band is made of bamboo that is 2.54 cm thick. Suitable padding and straps are also provided.







These are just a few examples of the search for cheap, and culturally acceptable braces in India. For more and detailed information contact these organizations (addressgiven at the end of the book)

Viklang Kendra also makes longer above knee braces and braces, that go up to the hip.

CHAPTER 60

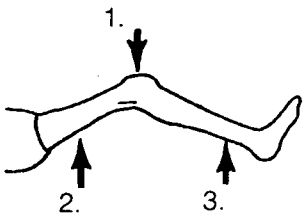
Correcting Joint Contractures

In this chapter we discuss different **aids used for gradually straightening limbs** have joint ***contractures.***

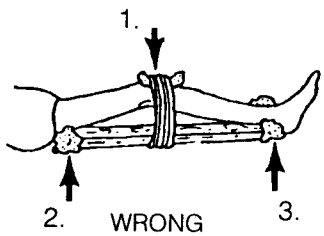
Information on contractures, their causes and prevention is in Chapter 8. Exercises to prevent and correct contractures are in Chapter 43. For other references to contractures, see the Index, p. 779.

Joint contractures can often be gradually straightened with casts or braces that **gently** but firmly hold the joint in a stretched position for a long time. We stress **gently** because unless great care is taken **it is very easy to cause injuries.**

To straighten a *limb,* 3 areas of pressure are needed.

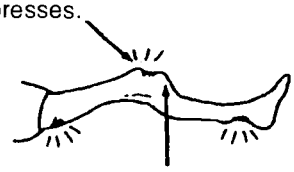


In **theory,** the leg could be straightened like this.



WRONG

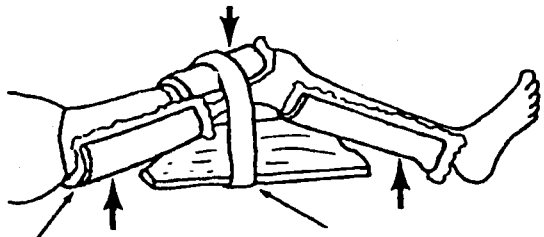
In **fact,** this would cause **pressure sores** on the **small areas** where the splint presses.



Also, the knee could be *dislocated* if the calf is not supported while stretching.

Always use wide areas of pressure. Avoid pressure on the knee, behind the heel, and over bony areas.

BETTER

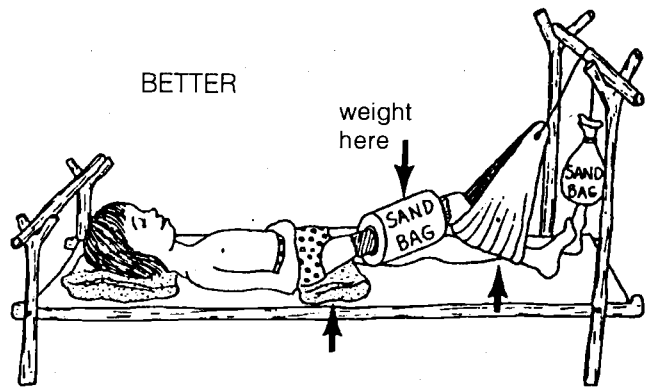


well-padded pieces of cardboard tubes, plastic, plaster, or bamboo

tight strap or band of car inner tube

If a child stays in bed, a stretching aid like one of these might work. (But try to keep the hip straight, so that the aid does not cause a hip contracture while it straightens the knee.)

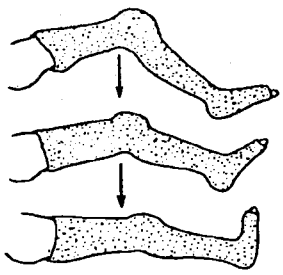
BETTER



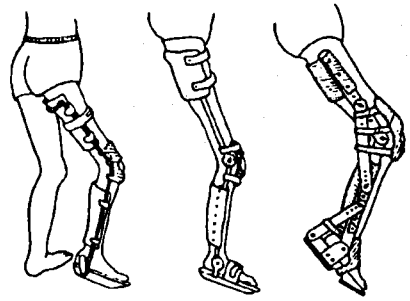
There are several ways to straighten contractures that let the child continue to move about. These include:



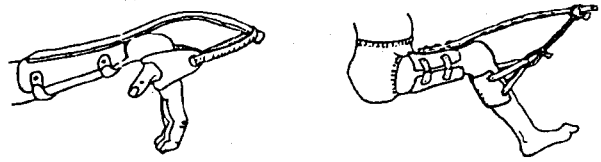
1. a series of plaster casts



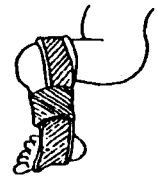
2. adjustable braces



3. elastic stretching aids of bamboo or inner tube



4. adhesive strapping



The advantages disadvantages of the first 3 ways are discussed on p. 95. **It is important you read this before deciding which one to use for a particular child.** The 4th method (strapping) is used mostly on clubbed feet of newborn babies (see p. 689).

HOW TO CORRECT CONTRACTURES USING PLASTER CASTS

The example we give here is for the knee, but the basic methods are the same for contractures in ankles, feet, elbows, and wrists.



Correcting contractures with casts. (PROJIMO)

Casting the leg

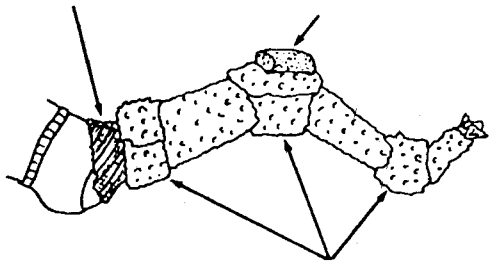
FIRST WEEK

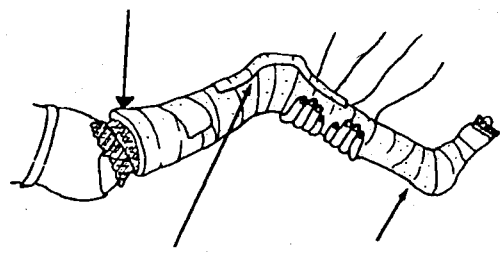
1. Put stockinette or a close fitting cotton stocking on the leg. Avoid wrinkles.

3. To protect the knee, it helps to put a soft sponge or piece of sponge rubber over the knee.

5. Put a plaster cast on the leg. Be sure it reaches high up the thigh.

7. Holding the calf below the knee, gently straighten the leg as far as it will go, without using force.





2. Put cast padding or cotton roll (or wild kapok) evenly around the leg.

4. Put extra padding around the thigh, the knee, and the ankle.

6. Put lenghtwise strips of plaster for reinforcement over the knee.

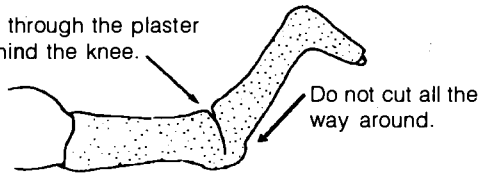
8. Position the foot at a right angle (or as near to it as you can without using force).

STRAIGHTENING THE CAST WITH WEDGES

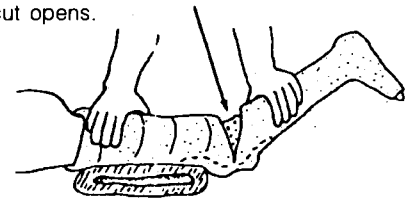
The cast is straightened a little every few days. In a small child or a person with recent contractures, it can be done every 2 or 3 days. In persons with old contractures, progress will be slower. To save on costs, change the cast every week or 10 days.

SECOND WEEK

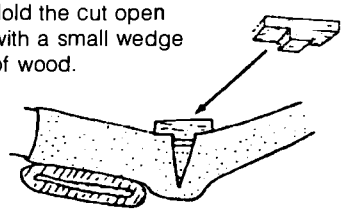
1. Cut through the plaster behind the knee.



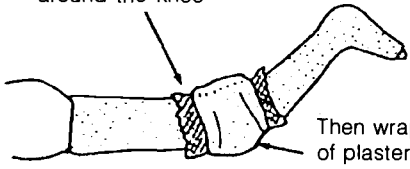
2. Use steady, **gentle** pressure so that the leg straightens a little and the cut opens.



3. Hold the cut open with a small wedge of wood.



4. Wrap a piece of cloth around the knee



Then wrap a thin ring of plaster around it to keep around it to keep the wedge in place.

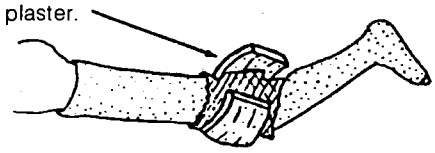
CAUTION: When stretching the leg, use gentle, steady pressure until **it begins to hurt a little.** Do not try to advance too fast, as you may cause permanent damage to ***nerves, tendons,*** or the joint.

For a day or so after stretching, the child may have some discomfort behind the knee. This is normal, unless it hurts too much. You can give aspirin. If the child complains of pain over pressure points or bony bumps, remove the cast or cut open a window in the cast to check if a sore is forming.

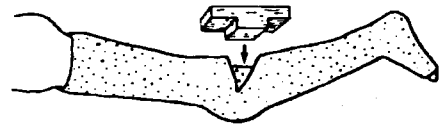
WARNING: When casting a child who does not feel in his limbs, take great caution to avoid pressure sores, and use very little pressure.

THIRD WEEK

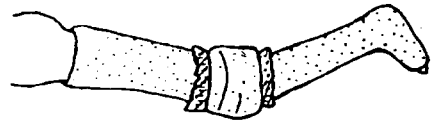
1. Cut and remove the ring of plaster.



2. Gently stretch the joint and put in a wider wedge.

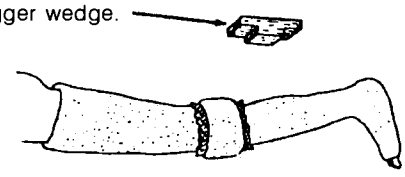


3. And cover it with a new ring of plaster.



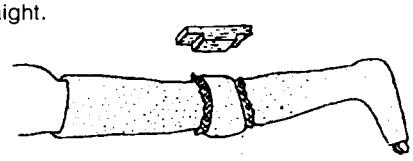
FOURTH WEEK

Each time you change the ring, put in a bigger wedge.

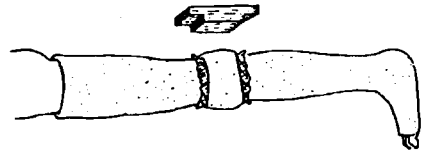


FIFTH WEEK

Continue casting until the knee is completely straight or bends backward just a little. Then use a brace for at least a few weeks (day and night) to keep it straight.



SIXTH WEEK



The time to straighten a contracture may vary between 2 weeks and 6 months-or more. If the leg stops straightening for 3 or more cast changes, stop casting and try to arrange surgery.

Straightening a leg that is hard to stretch

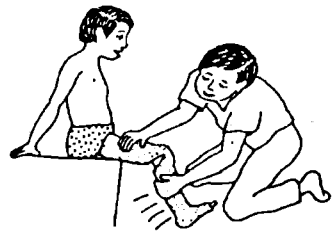
In an older child who has a knee contracture with strong *muscles* that bend the knee, it may be hard to straighten the knee more with each cast change.



If the leg does not move when you pull it ask the child to...



When he relaxes, keep pulling and the leg should straighten a little.



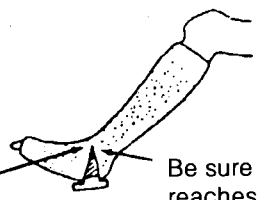
Repeat this several times while you steadily pull the leg. Each time the knee should straighten a little more.

Straightening a tiptoe contracture

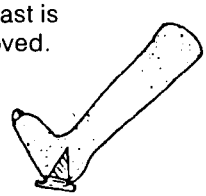
A foot with a contracture like this,



can sometimes be straightened with casts and wedges.



Try to overcorrect the contracture so that it will rest easily at a (90°) right angle when the cast is removed.



Do not let the child walk on the cast until the day after it is put on-and then only if you put a 'walking heel' on it. Otherwise the sole of the cast will become floppy and will not help. Active children need very thick plaster on the bottom of the foot.



CAUTION: The above method of correcting tiptoe contractures sometimes causes pressure sores here.

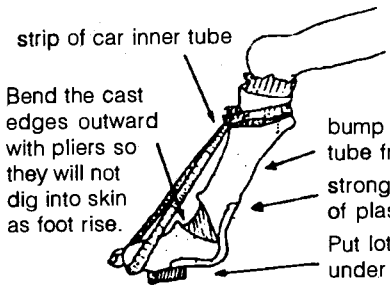


To prevent pressure sores, it often works better to cut a complete ring out of the cast.



For more precautions, see p. 691, on the casting of club feet.

For the child who lives too far away to have her cast changed every few days, you can try to make an aid that will gradually pull the foot up without needing frequent cast changes. Here is one idea.



CAUTION: It the child is sent home with a cast, **be sure the family knows the danger signs.** If any of these appear, have them quickly bring the child back or remove the cast themselves.

Danger sings:

- Constant, severe pain – especially in areas where pressure sores can occur
- a darkening or change of colour in the toes
- numbness or burning.
- a smell like rotting meat (a late, very serious sign)

To take off the cast without tools, in an emergency, soak it in warm water and unwrap or tear it apart.

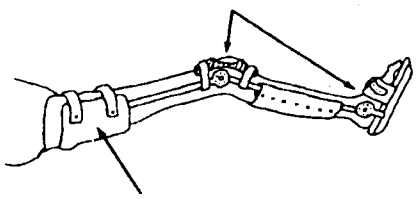
Note: This cast is not as strong as a fully covered one and will not last on a very active child. It will usually only work on a child without much sideways deformity of the foot or ankle. The cast may need to be changed 2 or 3 times as the foot straightens.

HOW TO CORRECT CONTRACTURES USING ADJUSTABLE BRACES

The advantage of these braces is that children do not have to visit the ***rehabilitation*** center so often to have them adjusted. The family can adjust them at home.

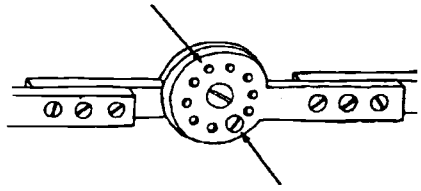
Orthopedic suppliers in some countries sell special knee and ankle joints that can be locked in different positions. But these are very expensive. However, a skilled village craftsperson can put together something similar.

Knee and ankle joints can be adjusted every few days to gradually straighten the joints.



leather or plastic cuffs

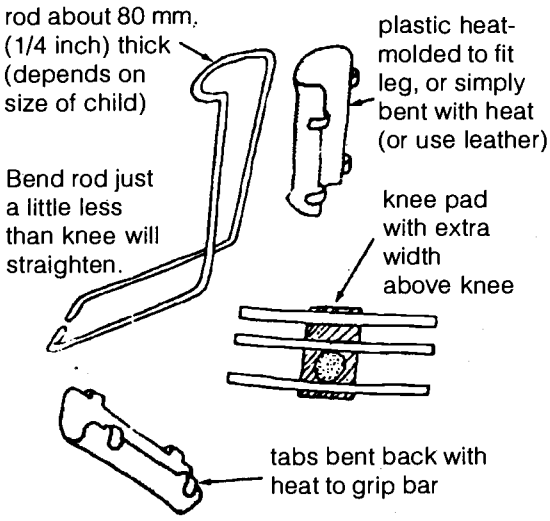
Space the holes on the 2 pieces differently so that lining them up allows a range of small adjustments.



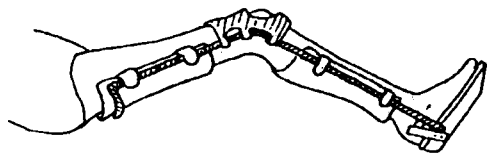
adjustment screw or pin

A much simpler low-cost model can made of **round of flat metal bar.**

Round metal rod (re-bar)

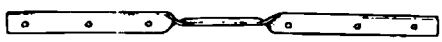


These metal bar braces are used in a way similar to a standard above-knee brace (see p. 663). Every 2 or 3 days bend the bar a little straighter at the knee. The brace can be made cheaply, and can be removed for walking and exercise, and to check for sores. As the leg becomes straighter, any of these braces can be used as a regular walking brace with a *clog*.

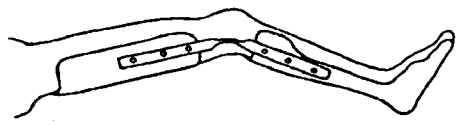


Flat metal bar

Use flat steel bar that is strong enough to hold leg firmly.

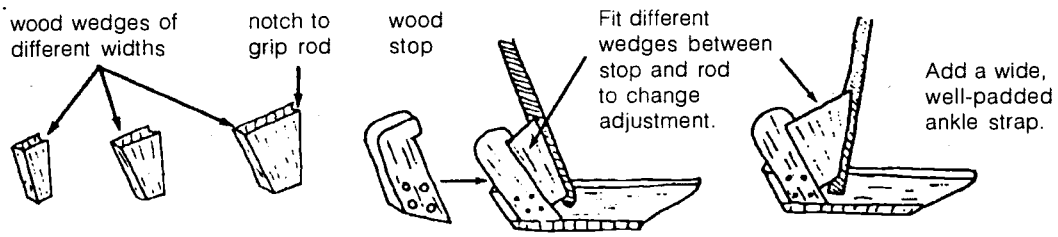


Twist the middle part of the bar in a way so that it can be bent for easy adjustments.



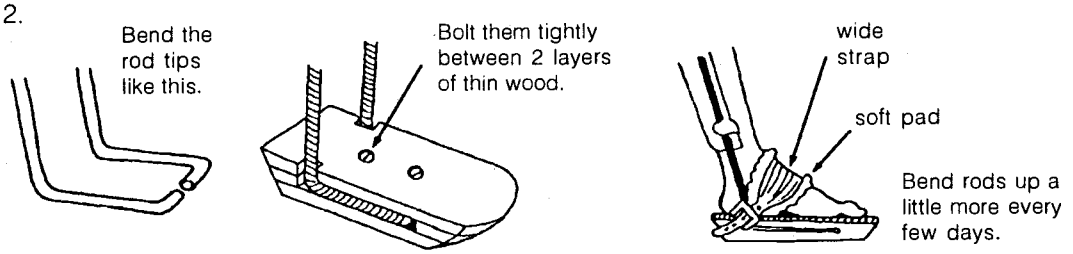
Two designs for adjustable braces to correct ankle contractures

1.

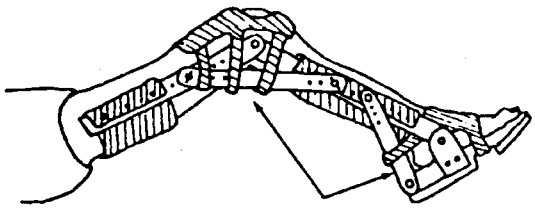


Note: This design is complicated to make, but can be adjusted while the brace is on the child.

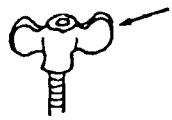
2.



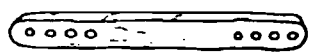
An adjustable wood brace for knee and ankle contractures



The positions of these 2 cross pieces can be changed to adjust the angle of the knee and foot.



Using 'wing nuts' makes it easier to remove the bolts for clamping the position of the cross pieces.



Use thin pieces of hard wood about 2 cm. wide and 6 to 8 mm. thick.

For **homemade aids to straighten contractures, using car inner tubes and other elastic or springy material**, see p. 95.

WARNING:

If a knee looks like this, it is probably dislocated. Trying to straighten it could make the dislocation worse. Take great care to put pressure only on the leg just below and behind the knee, not at the foot. Gradually try to correct the dislocation (bring the lower leg forward) before trying to straighten. If possible, get advice or help from an experienced health worker or specialist.



CHAPTER **61**

Correcting Club Feet

> ***Note:*** In Chapter 11 we discussed club feet. We suggest you read pages 128 and 130 before trying to correct a club foot.

The younger a child is when you begin, the more easily and quickly her foot can be straightened. **For best results, begin 2 days after the baby is born.** If the child is over 1 year old, usually a good correction is only possible with surgery. Ways to predict how easy or difficult correction may be for a particular child are listed on p. 130.



club foot

Method 1: STRAPPING

This method works well in a baby with mild to moderate clubbing, especially when the foot can be put into a nearly normal position. The method is easier and cheaper than casting, and sometimes gives better results. You will need:

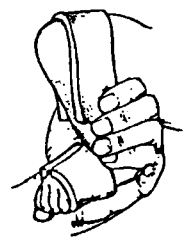
- tincture of benzoin (to paint on the skin to help the adhesive felt stick firmly. Zinc oxide in the tincture will help protect the skin.).
- cotton wool.
- adhesive surgical felt (padding) 8 mm. thick and at least 2.5 cm. (1 inch) wide.
- adhesive tape (sticking plaster) or zinc oxide strapping 2.5 cm. wide.

1. Paint tincture of benzoin on the skin areas to be covered by the tape.
2. Hold the baby's foot like this and gently straighten it as far as you can without forcing.

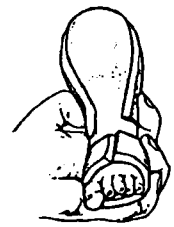


3. With the knee bent as far as possible, stick strips of felt around the foot and over the knee and leg as shown.

SIDE VIEW

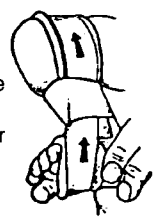


FRONT VIEW



SIDE VIEW

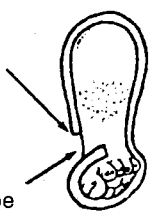
4. Stretch adhesive tape over the felt Start on the outer side of the foot, go around the foot, up over the knee, and down the other side. Use the tape to pull the foot into a better position.



FRONT VIEW

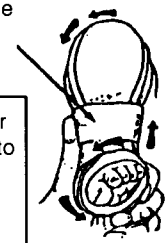
Tape coming down leg ends here

no tape here



FRONT VIEW

5. Put a second piece of tape around the leg twice here to hold the first tape.



> ***CAUTION:*** 10 minutes after putting on the tape, check to see if any part of the foot has turned dark. If so, look for the trouble spot and try to adjust the strapping if it stays dark, take everything off and start again.

Every 2 or 3 days, tighten the correction by stretching new tape over the old, in the same way. On the 7th day, remove everything and leave the leg free until the next day on the 8th day, apply new felt and tape.

Exercises during strapping

While the baby's foot is strapped, someone in the family should do stretching exercises on his foot every time he is fed or changed (at least 8 times a day).

1. Hold the baby's leg like this and **turn his whole foot UP and OUT.**

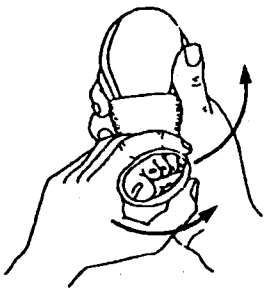
   Hold and count to 10. Repeat 10 times.

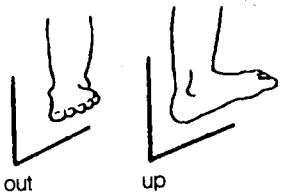
2. Turn it as if you were trying to touch the little toe to the outer side of the knee.

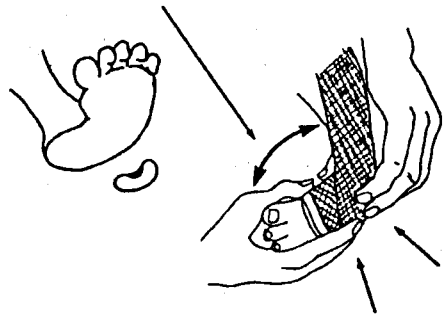
   The strapping and exercises should be continued until the foot is **overcorrected** (bends outward a little).

3. If the foot is shaped like a bean also do an exercise to stretch the foot in the opposite direction of the deformity, like this.

4. After stretching the baby's foot this way, help the baby to stretch it himself by tickling the outer edge of his foot.







If the foot is not straightened completely within about 3 months of strapping and exercises, surgery is probably needed.

Method 2: PLASTER CASTS

This method uses a casting technique similar to the one for correcting contractures (see Chapter 60). A club foot is gradually straightened in 3 stages:

Stage A

Straighten the inward bend so that the foot points **down.** Do not yet begin to lift the foot.

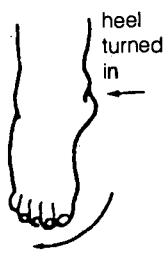
Stage B

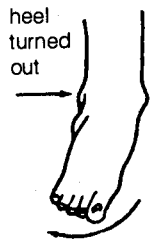
Overcorrect so that the foot points **down** and **out.** Keep the foot in this position **until the heel no longer turns in** but is straight or turns out just a little.

Stage C

Now bring the foot up, making sure that the outside of the foot is higher than the inside. **Overcorrect.**









Stage A

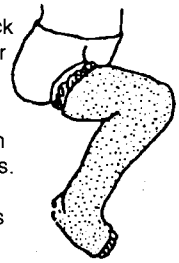
1. In a young baby it is often necessary to **cast the whole leg with the knee bent** to keep the cast from slipping down. First, wrap cotton padding evenly around the whole leg.



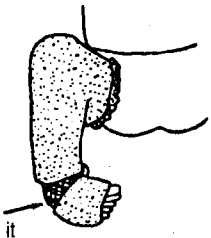
Put extra thick padding over bony spots (see p. 560).

Put bits of cotton between the toes. (Take them out after the foot has been cast.)

2. Cast the leg and foot. Make the cast especially thick around the knee and heel, where he is more likely to bump it.

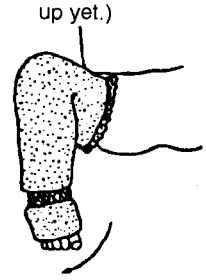


3. After the plaster is dry, cut out a wide ring from heel to mid-foot.



Make it wider on this side.

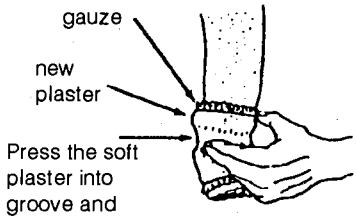
4. Gently and slowly begin to stretch the foot OUT and DOWN. (DO not try to bring it up yet.)



5. To keep edges of cast from hurting the skin, bend them out with pliers.

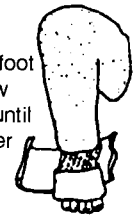


6. Put a ring of cotton or soft gauze over the foot and cover with new plaster bandage.



Press the soft plaster into groove and smooth with fingers.

Hold the foot in the new position until the plaster hardens



7. Once or twice a week take off the outer ring of plaster, bend the foot down and out a little more, and cover with a new ring of plaster.

Repeat Step 7 until the foot bends outward a little. This usually takes several weeks.

Stage B

1. Remove the whole cast and check the position of the heel.



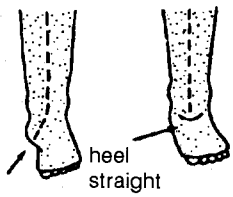
Often the heel still bends in even after the bend of the foot has been corrected.



2. If so, keep casting the foot in a **down** and **out** position until the heel is straighter

BACK VIEW

BEFORE AFTER



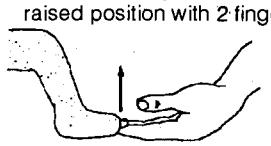
Stage C

1. After the sideways twist of the foot and heel is corrected, begin to raise the foot, using casts.

Take care to keep the toes straight.



2. As you wrap the foot with plaster bandage, hold it in a raised position with 2 fingers.



4. Keep raising the foot little by little using the same casting method as before.



Bend up cast edges with pliers

3. Hold the foot up as the plaster dries.



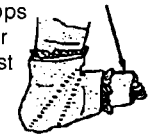
(***CAUTION:*** Be very careful cast does not pinch or dig into skin here.)



As you hold the foot keep it turned outward so that the little toe is always higher than the big toe.



5. Raise the foot a little in this way once or twice a week until it is as high as this, or until it stops raising for 3 or 4 cast changes.

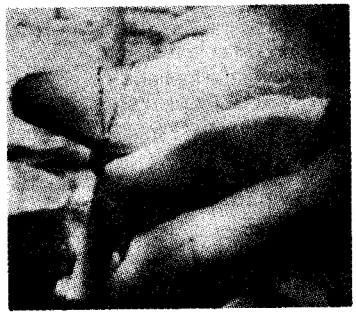






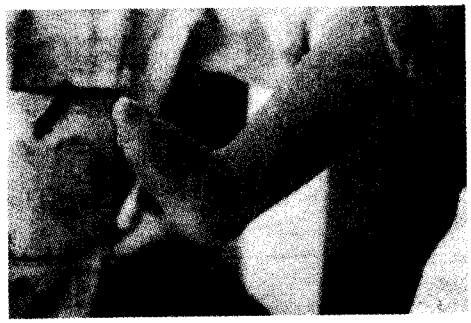
This child was born with a club foot. Village *rehabilitation* workers used a series of casts to straighten it. First they corrected the inner bend of the foot.







Then they gradually lifted her foot by cutting out rings on the cast, closing the space, and holding it closed with a new strip of plaster. (See p. 691)



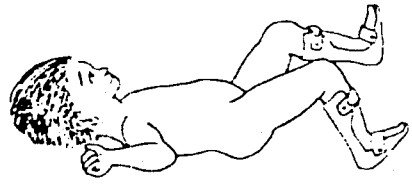
After 4 months of casting, the foot was in a good position.

IMPORTANT

After a club foot has been corrected, great care is needed to prevent it from coming back.

Both exercises and braces are essential. After strapping or casts have been removed, continue the recommended stretching exercises twice a day (see p. 128). Braces for use after correcting club feet are on p. 130.

Many children need to wear braces until they stop growing (age 13 to 18). If the problem keeps returning, surgery is probably needed.



This child who had club feet needs to use braces day and night, at least until he begins to walk, and still at night after that.

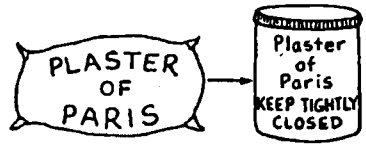
Check his feet regularly, for years, for any sign that the foot is beginning to turn in again. Improved bracing may be required.

CHAPTER 62

Homemade Casting Materials

PLASTER BANDAGES

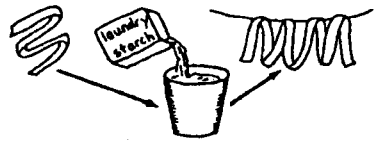
Although commercial plaster bandages work best, they are very expensive. You can make homemade plaster bandages for as little as one tenth the cost. Or some of the disabled children can learn to make them. You will need:



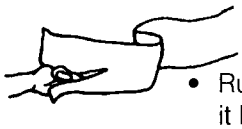
- **plaster of pairs.** If possible, a high-quality type such as dental plaster of Paris. Keep it in a tightly closed moisture-proof container.
- **gauze cloth or crinoline.** Crinoline, which is a high-quality open mesh cloth, works best. Good quality gauze can also be used. Holes should be about 8 to 10 per cm. (20 per inch). Cheesecloth also works, but not as well.



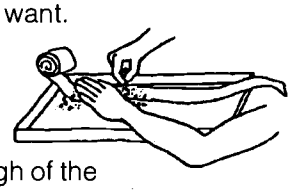
HOW TO PREPARE:



- If you use gauze or cheesecloth, first dip it into a weak solution of laundry starch and let it dry. This helps the bandage keep its shape.

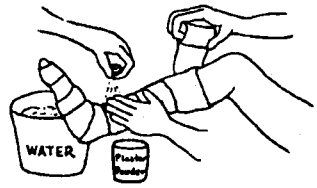


- Cut the cloth into strips of the width you want.
- Rub plaster powder into the cloth and roll or fold it loosely. **Do not roll it tightly** or the inner part will not get wet when dipped for use.

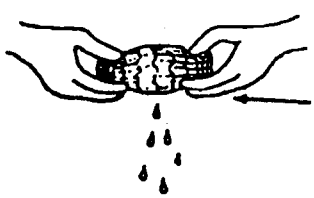


The most common problem is that the gauze does not hold enough of the plaster powder. Even if you put on a lot, some powder always falls out. The test is when you apply the wet bandage. As you rub each layer into the next, the threads of cloth should disappear into the smooth, wet, plaster surface. If not, there is not enough plaster and it will not set hard.

Suggestion: Have some dry plaster power ready when you are casting. If needed, sprinkle a little power over each layer of bandage and rub it smooth with wet hands. Add more to the final layer and rub it in to form a polished surface.



Storage: Wrap the plaster bandages in old newspaper or plastic bags and store in an airtight container. Do no prepare too many at a time. They can absorb moisture and spoil.



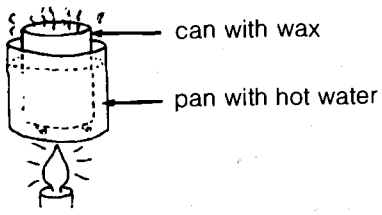
CAUTION: When wetting for use, up to a third of the plaster may be lost in the water. To reduce loss, put bandage gently into water and then let it drip. If you squeeze it, hold the ends of the roll and gently squeeze toward the center.

Homemade plaster takes longer to get hard than commercial 'fast-setting' plaster. **To speed up hardening, heat the water or add a little salt to it.**

CASTS MADE OF WAX

To prepare a mold of a leg for making plastic braces, the first (hollow) cast can be made of wax instead of plaster. Use either candle wax (paraffin) or beeswax. **Wax can be much cheaper than plaster bandage, especially if the wax is re-used. To make a wax cast:**

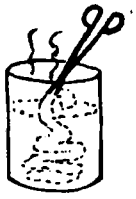
1. Melt the wax in a can placed in hot water



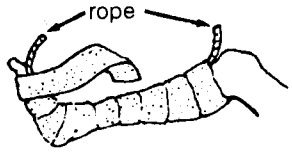
2. Cut several strips of soft absorbent cloth.



3. Soak the cloth in hot wax

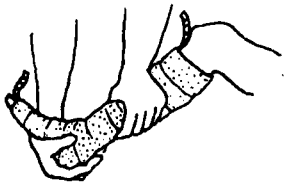


4. When it has cooled enough not to burn, wrap the waxed cloths around the foot.

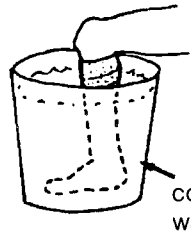


Note: Before putting on the wax, you can cover the foot with 'stockinette'. Also place a rope or strip of plastic along the top of the leg to make cutting the cast easier. (See p. 672)

5. While the wax is still warm and soft, rub and press it against the leg.



6. Hold the foot in the desired position until the wax hardens. (To speed hardening, you can put the foot in cold water.)



7. Cut the wet cast along the rope, and carefully remove it. Go on with the other steps as described on p. 672

Re-using the wax: After the positive plaster mold has been made from the wax cast, the wax can be re-used. Heat up the pieces of waxed cloth and use them to form a new cast. Or boil the waxed cloth in water, holding the cloth under the suface with rocks or metal. The hot wax will rise to the surface. When it, cools. lift it off and re-use it.

OTHER POSSIBLE MATERIALS FOR CASTING OR MOLDING

Many materials can be used for casts. **Most have the disadvantage that they take a long time to harden.** Possibilities include:

1. **Papier mache.** Very slow hardening. Careful use of a heat lamp or 'hair dryer' speeds drying.
2. **Traditional cast materials.** For example
   - In Mexico, the juices of certain plants, boiled into a thick syrup and soaked into a cloth, will harden into a cast (see **Where There Is No Doctor**, p. 25).
   - In India, traditional bone setters make casts using cloth covered with egg white mixed with flour.
3. Flour made from cassava (manioc) is also used in India to make casts.

To make the solid (positive) mold of a limb (see p. 672). 'building plaster' works well. (Wax cannot be used because it melts when hot plastic is placed over it.) Clay also works, but takes several days to dry.

CHAPTER **63**

Developmental Aids

In this chapter we look at the design details of aids for **lying, sitting, standing, balance, use of hands,** and **communication.** Aids for walking are in Chapter 64.

Whether or not a particular child needs an aid, and what kind of aid she needs, must always be carefully and repeatedly evaluated. An aid that helps a child at one level of development may actually hold her back at another. When considering aids, we suggest you first read the chapters on child development, those covering the particular ***disability*** of the child, and Chapter 57.

> ***Note:*** Many developmental aids have already been shown in PART 1 of this book, especially in Chapter 9 (cerebral palsy), and in Section C, on child development. Aids and equipment for play and exercise are in PART 2. Chapter 47 (Playgrounds). Wheelboards and wheelchairs are in Chapters 65,66, and 67.

Lying aids

Lying face down is a good position for a child to begin to develop control of the head, shoulders, arms, and hands, and also to stretch ***muscles*** in the hips, knees, and shoulders. However, some children have difficulty in this position. For example:



Rosa cannot lift her shoulders. She has to bend her neck far back to lift her head.

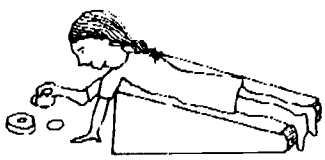


Baby does not have enough control and balance to reach our his arms.

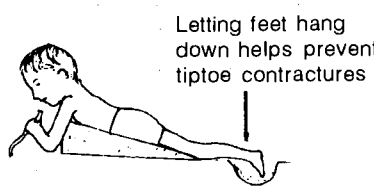


A firm pillow under the chest may help both these children to lift their heads better and to reach out.

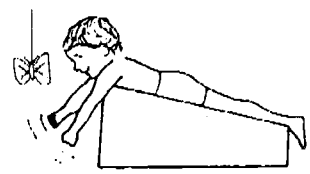
A **'wedge'** or slanting support is often helpful. The height depends on the needs of the particular child.



Dina manages best on a wedge high enough so that she can lift herself up a little at arms length. Height is the length from wrist to armpit.)



Quaisar does better on a lower wedge, so he can lift up on his elbows. (Height is slightly less than length from elbow to armpit.)

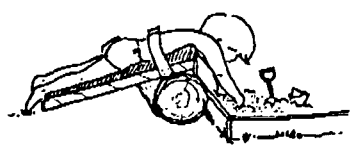


Armaan and others with little or no arm or hand control do best when their arms can dangle. She can see them moving when she moves her shoulders.

Wedges can be made with:



stiff foam plastic or layers of cardboard

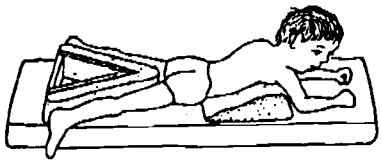


a log and a board with a soft foam cover

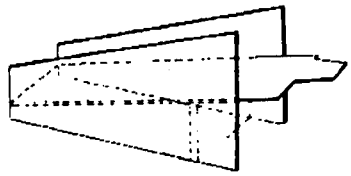


a stick frame

If necessary, a leg separator can be added (see p. 91).



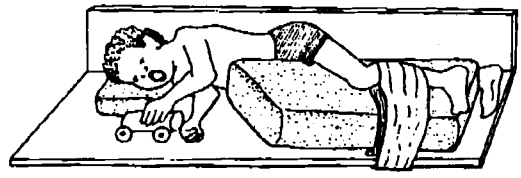
Or sides can be included for the child who needs to be *positioned* with supports or cushions.



Design from *Functional Aids for the Multiply Handicapped* (see p. 774).

Some children are able to control their shoulders, arms, and hands better when lying on one side.

A side-lying frame may be helpful for some children with severe cerebral palsy. Try cushions or padded blocks of different shapes until you find what works best. Use straps only if clearly needed to keep a good position.

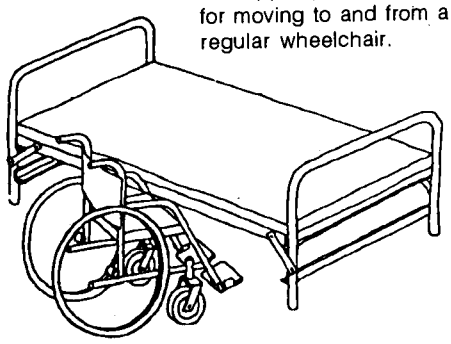


Also are lying frames for straightening hip flexion contractures (p.91 and 96), and lying frames with wheels (p. 746 and 747).

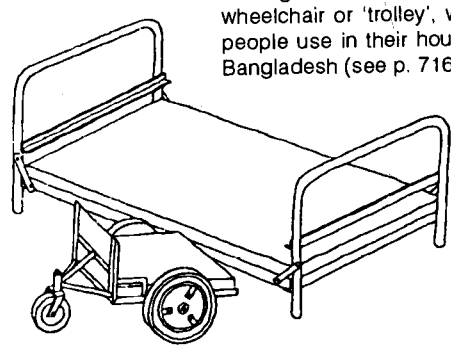
ADJUSTABLE BEDS

This design from the Centre for the Rehabilitation of the Paralysed in Bangladesh adjusts easily from an upper position to a lower position.

The upper position is right for moving to and from a regular wheelchair.



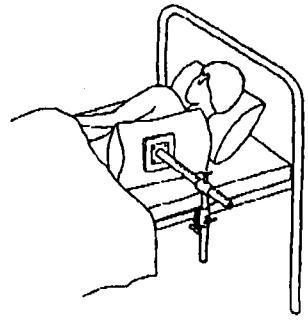
The lower position is right for moving to and from a low level wheelchair or 'trolley', which many people use in their houses in Bangladesh (see p. 716)



These metal beds and wheelchairs are welded together by paraplegic workers. For the 'coconut fiber' mattresses they use, see p. 233.

ADJUSTABLE BACK SUPPORT CLAMP

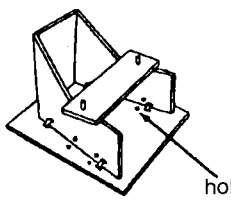
Supporting a severely *paralyzed* person so he lies on his side can be difficult Pillows easily move or slip. This simple clamp helps solve the problem. It was designed and made by disabled workers at the Centre for the Rehabilitation of the Paralysed, Dacca, Bangladesh (see p. 626).



CAUTION: To prevent pressure sores, be sure the child changes position often (see Chapter 24).

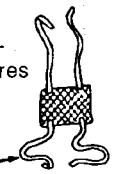
Sitting Aids

A wide variety of early sitting aids are included in the chapter on cerebral palsy. (see p. 109) Special seating ***adaptations*** for chairs and wheelchairs are a Chapter 66. Here we include a few more ideas:

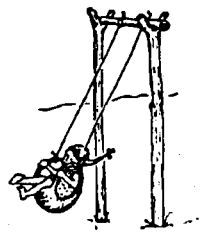


seat for child with ***spasticity*** who has knock-knee contractures (one of many possibilities, see p. 5)

holes for straps

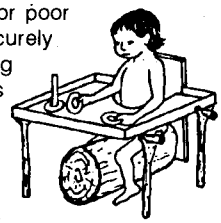


strap for keeping legs apart (one around each leg and tied through holes in sides of seat)

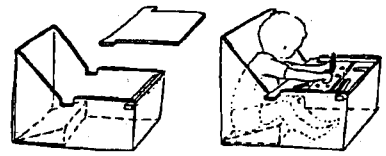


Tire seat or swing bends head, body, and shoulders forward to help control spasticity (see p. 515)

A log or roll seat helps the child with spasticity or poor balance sit more securely with legs spread. Log should be as high as the knees. Leave a little room between the cut-out circle in the table and the child's belly.



seat for a child with spasticity whose body stiffens backward

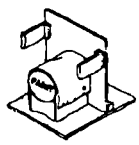


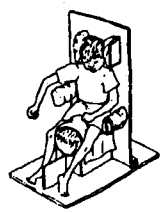
Design from *Handling the Young Cerebral Palsied Child at Home* (see p. 770).

OTHER IDEAS FOR HOLDING LEGS APART

from Don Caston and AHRTAG









A seat and table like this in the form of a fish on the ocean makes sitting in the special seat fun. So do the village-made toys (PROJIMO, seat design by Don Caston).

from other parts of this book



p. 5, 510



p. 5



p. 7



p. 91,109



p. 110



p. 735



p. 401



The seat can be used for straight leg sitting, or put on top of the table for bent-knee sitting. Other designs include 'squirrel' seats on 'tree' tables.

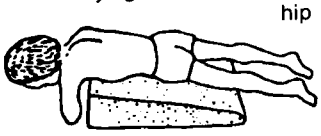
For more ideas on adapted seating, see Chapter 9, 36 and 66. Also, see scooters and walkers with roll seats, p. 110.

Standing aids (See also p. 111, 382, and 606.)

Many children who have problems with balance or control for standing may benefit from standing or playing in a 'standing aid'. Even for the child who may never stand or walk on her own, being held in a standing position with weight on her legs helps **circulation** and bone growth and strength.

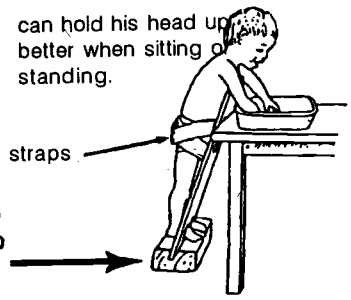
STANDING BOARD

Sometimes a child who does not have enough control or strength to hold his head up when lying.

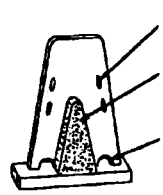


can hold his head up better when sitting or standing.

hip straps



A simple **standing board** can help hold the child in a stable position. This one leans against a table.

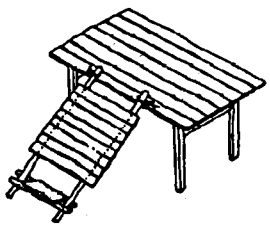


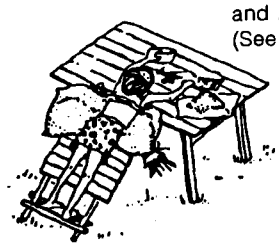
holes for straps

A knee separator can be added.

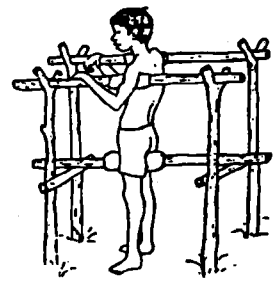
holes for feet (straps may also be needed)

LEANING BOARD





from Don Caston and AHRTAG (See p. 774.)



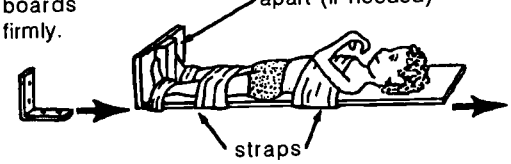
BACK-BOARD

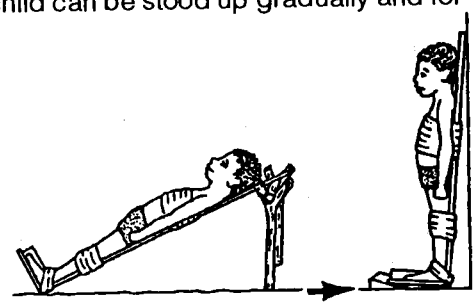
This can be used to gradually bring a child to a standing position. It is especially useful for older children who get dizzy if stood up straight too quickly. This can happen after a spinal cord injury or a long, severe illness. The child can be stood up gradually and for longer each day.

Use angle irons to hold boards firmly.

block to hold legs apart (if needed)

straps





STAND-IN TABLE

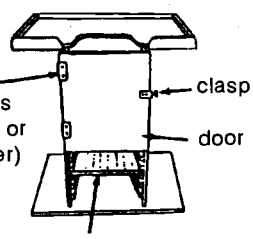


padded knee block

hinges (cloth or leather)

clasp

door

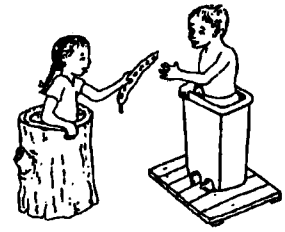


adjustable foot board for children of different heights

OTHER IDEAS



large tile or cement pipe



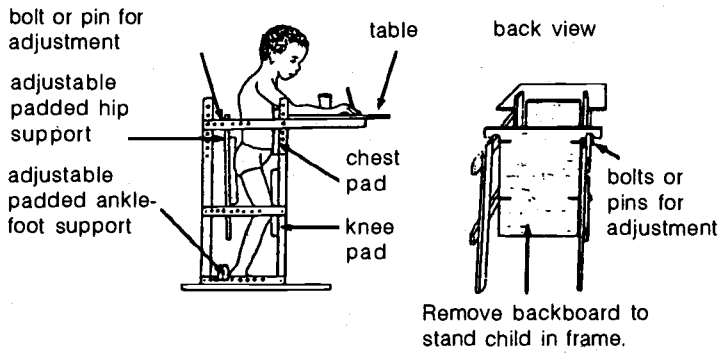
hollow log (like people use for bee hives)

plastic garbage container (Fasten it to a wide base to keep it from tipping over.)

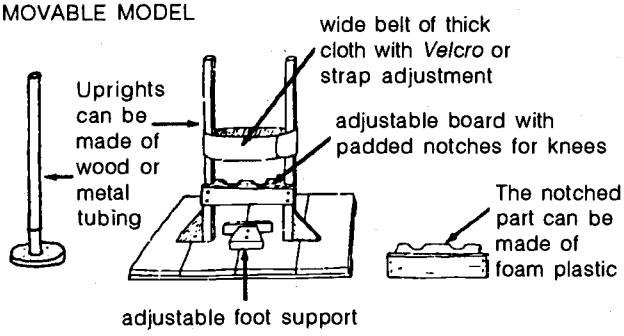
STANDING FRAMES

These are mainly for a child with contractures or painful joints who has difficulty standing straight. This child can gradually be straightened up.

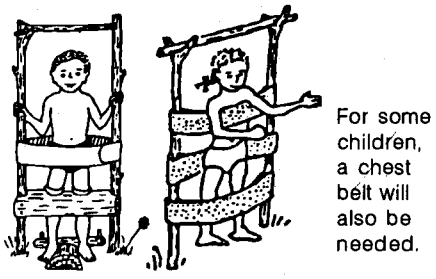
ADJUSTABLE MODEL



MOVABLE MODEL

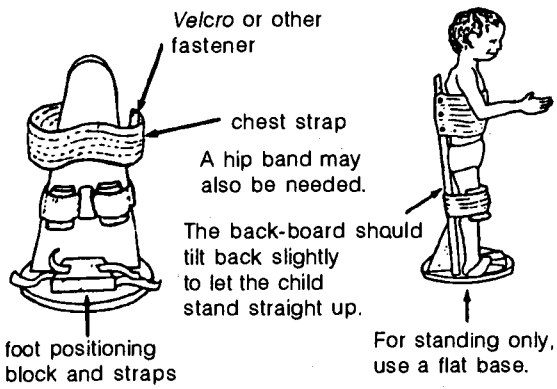


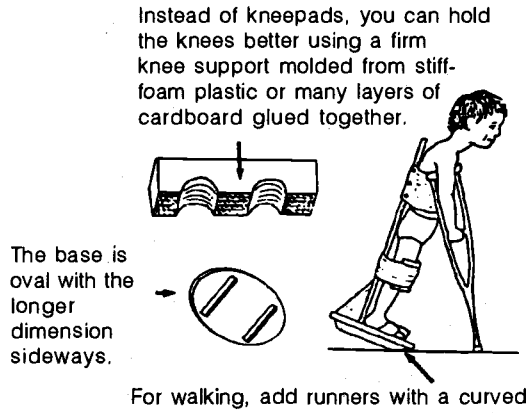
SIMPLE FIXED MODEL



STANDING-AND-WALKING FRAME

This is a useful aid to begin standing and walking, for children paralyzed or severely affected below the waist (paraplegia, spina bifida, diplegic cerebral palsy).

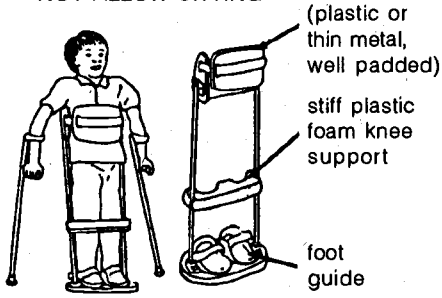




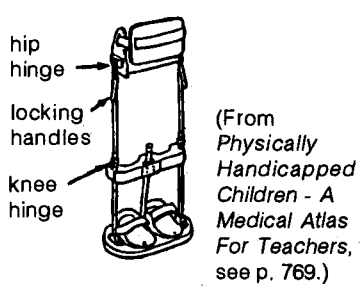
STANDING-WALKING BRACE

This has the same use as the standing-walking frame above, but is especially useful for children who need to learn how to walk before they are fitted for braces with a hip band or body brace.

DESIGN THAT DOES NOT ALLOW SITTING



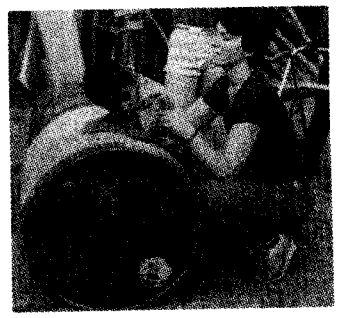
DESIGN WITH HIP AND KNEE HINGES TO ALLOW SITTING



(From *Physically Handicapped Children - A Medical Atlas For Teachers*, see p. 769.)

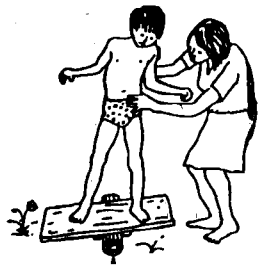
Aids for balancing and body control

Activities for improving balance are discussed on p. 119, 381, and 382. Here we bring together a few of the aids for balancing that are shown in different parts of this book, together with a few new ones.



An old drum or barrel makes a good 'roll' for exercise and positioning.

BALANCE BOARDS

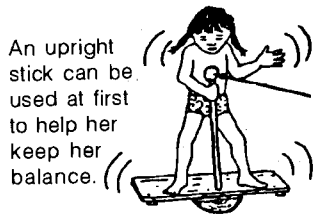


A balance board like this rocks less smoothly because the center rocker is so narrow.

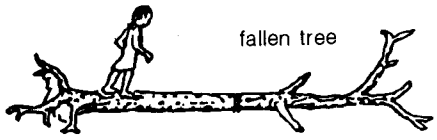


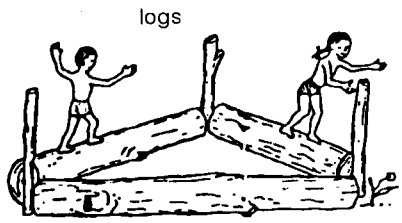
A wider rocker works better.

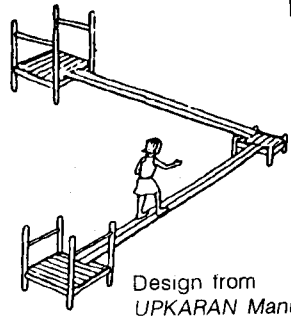




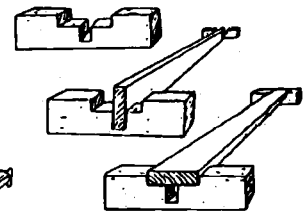
BALANCE BEAMS







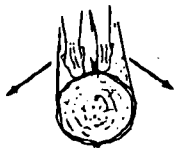
Design from *UPKARAN Manual*. (See p. 774).



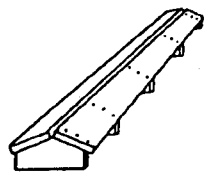
adjustable wide or narrow balance beam



For the child whose ankles bend in.



walking on a log helps bend the ankles outward.



Or the child can walk on standing boards, like this.

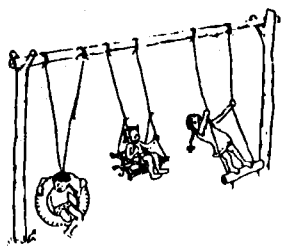


For the child whose ankles bend outward.

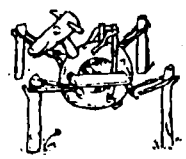


walking on boards like this helps bend the ankles inward.

To improve balance also see **swings, rocking horses and merry-go-rounds.**



p. 514 and 515



p. 516



p. 519

Other aids

Many aids not yet described in PART 3 have been described in other parts of this book. Here is a brief summary of some of these to give you basic ideas and tell you where to look. We also give a few ideas of aids not shown before.

EATING AND DRINKING AIDS


p. 126


p. 221


p. 264


p. 273


p. 398


p. 402


p. 403


p. 404


p. 525

TOILETING AIDS


p. 221


p. 418


p. 419


p. 419


p. 419


p. 421

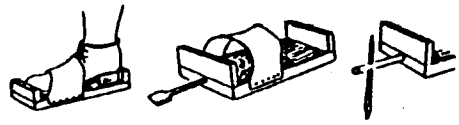

p. 421

HOLDING AND REACHING AIDS (Also see p. 6, 264, 273, 410, 412, 525, and 617.)


key holder


wash cloth mitten for washing dishes (or self)


button fastener


aids for working with feet

SPIRAL HOLDING AID

Cut a piece of heavy rubber tube like this.



Bolt it to a piece of plastic pipe or bamboo.



Use it like this.

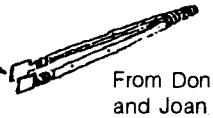



spiral attached to washstand



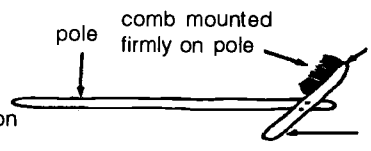
Note: For larger objects such as a knife or ruler, the spiral can be made of garden hose.

REACHING TOOL


sheet metal or heavy tin

From Don Caston and Joan Thompson

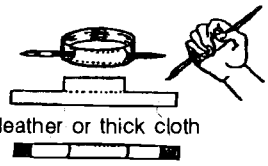
ALL-PURPOSE TOOL



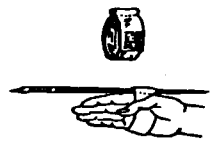
WRITING AIDS (Also see p. 221, 264, 273, and 607.)


pencil in a larger gum eraser


loop of car inner tube



Velcro

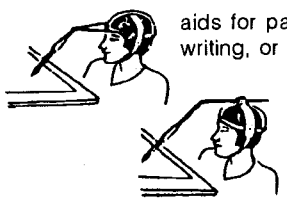

bamboo or tube or hose


rubber or plastic tubing

COMMUNICATION AIDS (Also see "Blindness" p. 302 to 303 and "Deafness" p. 310 to 331.)



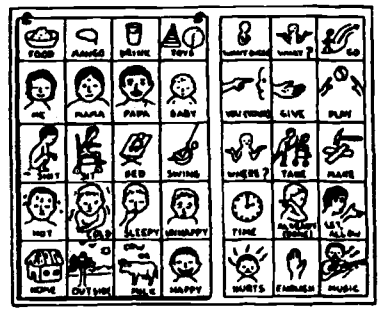
page turner
(p. 356 and 607)



aids for painting, writing, or pointing

From *Art and Disabilities*, (see p. 637).



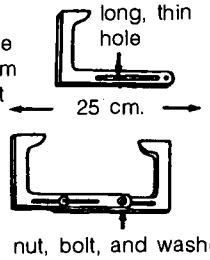


communication board

PHYSICAL EXAMINATION, MEASURING AND RECORDING AIDS

INSTRUMENT FOR LEVELING HIPS

Cut 2 pieces of thin plywood like this. Fasten them together so that they slide back and forth.

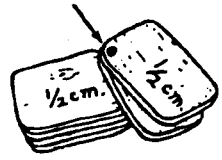


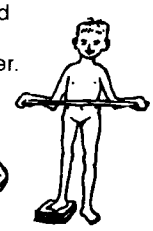
nut, bolt, and washer



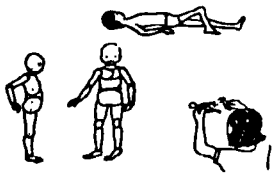
To use, close instrument around child's waist and push down against hip bones. Then raise or lower shorter leg until the instrument is level.

Cut rectangles of 1/4 inch thick boards and bolt them loosely together at one corner.

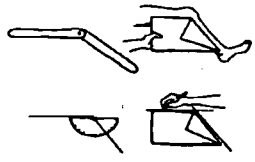




aid for measuring leg length difference (p. 36 and 669)



'flexikins' for measuring contractures and deformities (p. 45 to 52)



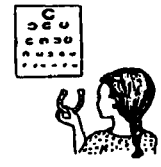
other methods for measuring contractures (p. 45 and 89)



rib-hump angle measurer (p. 183)



aids for hearing examination (p. 544)



aids for seeing examination (p. 546 and 547)

FOOT CONTRACTURE PREVENTION AIDS

Also see Chapter 60. "Correcting Joint Contractures," and Chapter 59. "Braces."



p. 91



p. 91



p. 91



p. 91



p. 215

EXERCISE AIDS



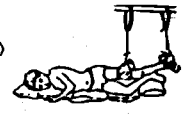
p. 5



p. 79



p. 161



p. 165



p. 166



p. 169

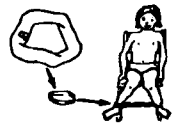
inner tube



p. 217



p. 272



p. 461



p. 476



p. 480



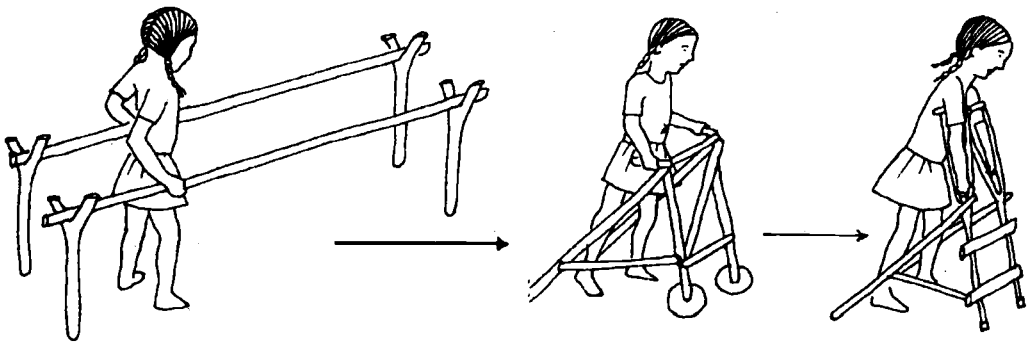
p. 641

CHAPTER 64

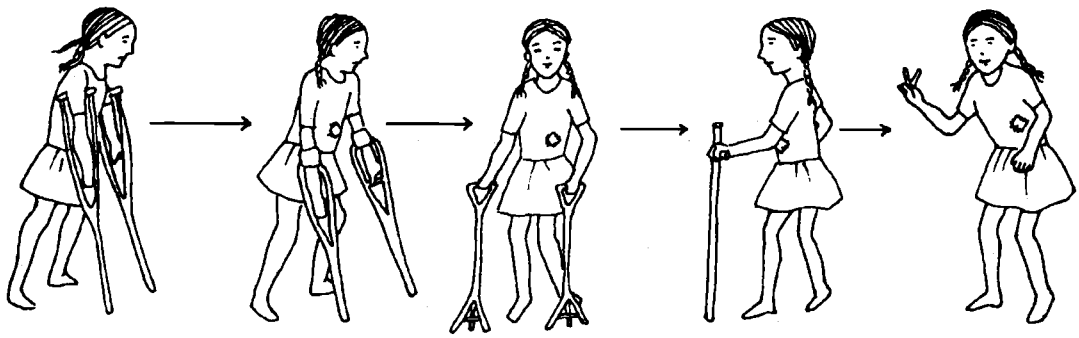
Walking Aids

In designing aids for a child, we need to think not only about her type and amount of *disability*, but also the stage of progress she is at. For learning to walk, she may progress through a series of stages and aids. Here is an example:

1. Parallel bars
2. Wheeled walker
3. Crutches modified to form walker



4. Underarm crutches
5. Below elbow crutches
6. Cane with wide base
7. Walking stick (cane)
8. If possible, no aids at all



In this chapter we show a variety of aids for walking. Most can be made easily out of tree branches or wood. Some can be made from building construction bars (reinforcing rod) or metal tubing, and may require welding.

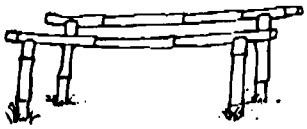
We include these ideas not to ask you to copy them, but with the hope that they will 'trigger' your imagination. Take ideas from these designs, and use the materials you have at hand. When possible, make your aids to meet the needs of the individual child.

At a village ***rehabilitation center***, it helps to have a wide selection of aids on hand, so that you can try different ones on a particular child to find out what works and what she likes best.

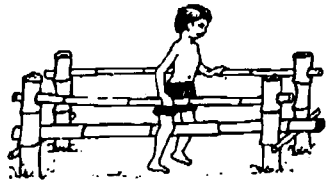
Parallel bars

Simple designs for outdoor parallel bars, both adjustable and non-adjustable, are included in Chapter 47 on playgrounds, p. 511 and 519. On p. 511 we also give suggestions for adjusting the bar height to meet the needs of the individual child. The designs shown are:

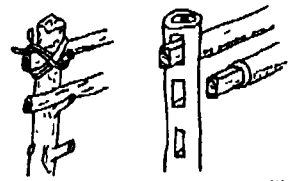
OUTDOOR BARS



simple, non-adjustable bars (bamboo, wood, or metal)



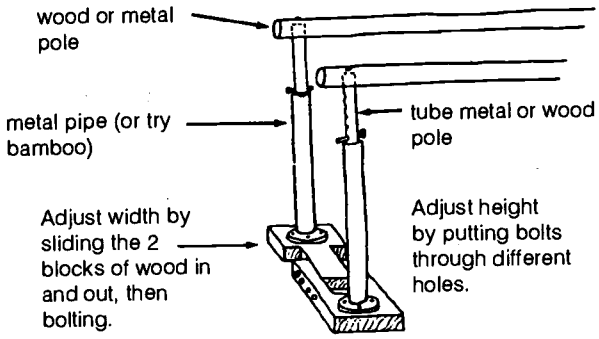
bars with a leg separator for a child whose knees pull together



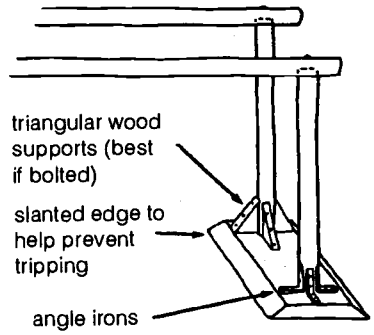
2 designs for bars with adjustable height

INDOOR BARS (design details for two of several models)

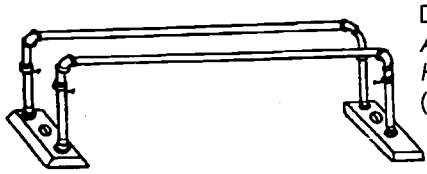
ADJUSTABLE MODEL



NON-ADJUSTABLE MODEL

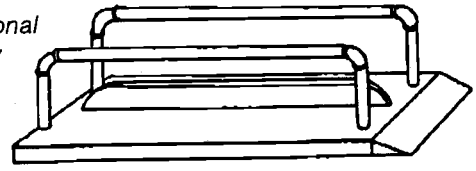


IRON PIPE BARS



NON-ADJUSTABLE BARS

Design from *Functional Aids for the Multiply Handicapped.* (See p. 774.)

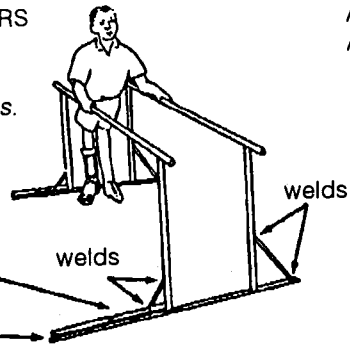


WITH FOOT DIVIDER

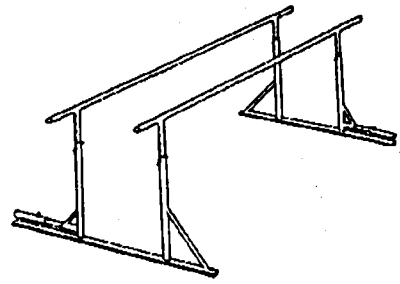
METAL CONDUIT TUBING

ADJUSTABLE WIDTH BARS

Designs from *Poliomyelitis.* Huckstep. (See p. 769).



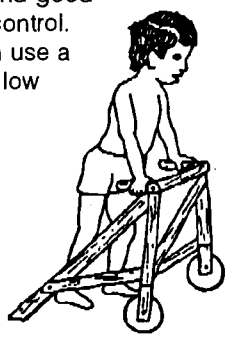
ADJUSTABLE WIDTH AND HEIGHT



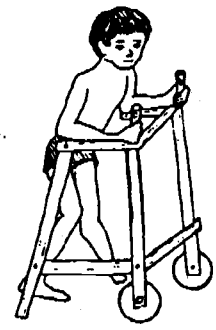
Walkers

There are many ways to make walkers or walking frames. Here we show a range from very simple to more complex. Choose the design and height depending on the child's needs and size.

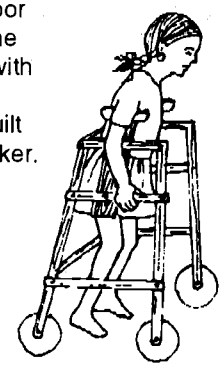
Jatin has strong arms and good body control. He can use a simple low walker.



Munna has weak elbows and poor balance or body control. He needs a higher walker with armrests.

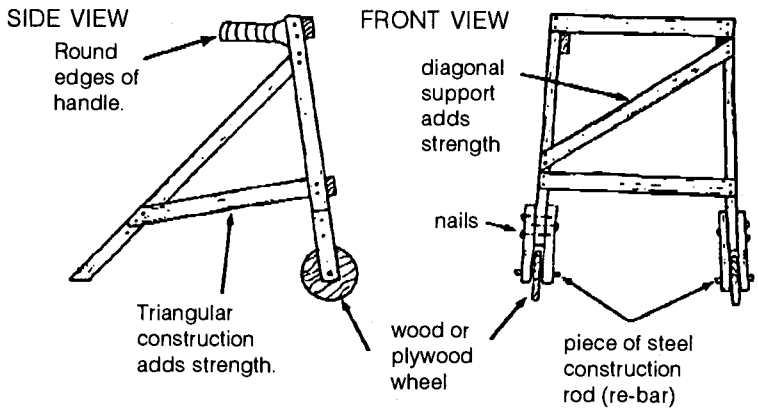


Anita has weak legs and poor balance. She does best with underarm crutches built into the walker.



The above walkers can be made with 2cm. x 4 cm. boards (such as those used on roofs to hold tiles), or thin trees or branches. The wood or plywood wheels roll easily when little weight is on them (when child pushes walker) but have a braking action when child puts full weight on them (when taking a step).



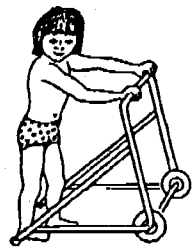


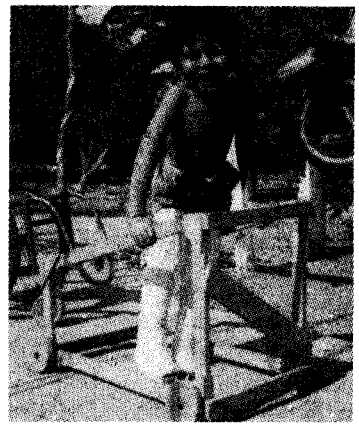
Finding the design that works best for a particular child often involves experimenting and changing different features.

For example, Zulekha has poor body and hip control, and tends to 'fall through' the space between her arms when the handgrips are upright.



A higher walker with a bar as the handgrip works better for her.





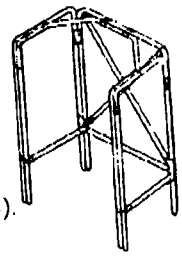
This walker with slanting bars lets a child hold it at the height that he finds works best.

These walkers can be made out of welded or bolted metal tubing.

Other walker designs

WALKER MADE FROM CANE, RATTAN, OR BAMBOO

Design from *Rattan and Bamboo Equipment For Handicapped Children*, J. K. Hutt (see p. 774).



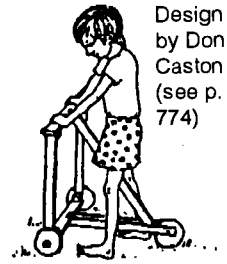
Joints can be tied with cane, ribbon, nylon string strips of car inner tube or whatever.

WOOD WALKER



Bamboo Walker made at the Viklang Kendra, Allahabad. (See p. 682)

Wood walker for a child whose legs need to be held apart.



Design by Don Caston (see p. 774)

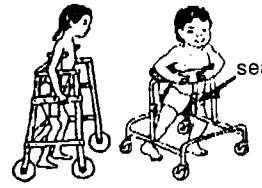
Note: A walker with no wheels is very stable but harder to move.



A walker with 2 wheels and 2 posts is fairly stable but easy to move.

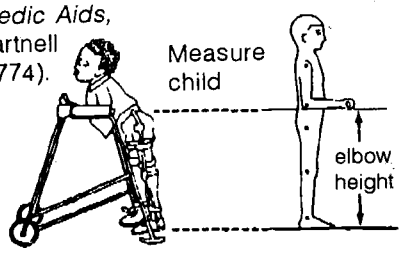


A walker with 3 or 4 wheels is very easy to move but can easily roll out from under the child (unless the child is seated).

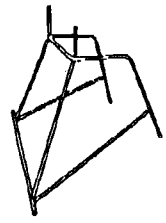


WALKER MADE FROM SOLID IRON ROD (RE-BAR) WITH ARMRESTS–WELDING REQUIRED

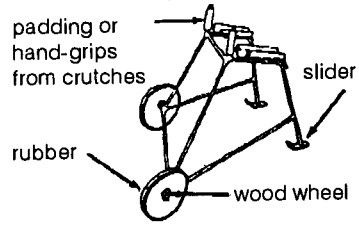
Design from *Simple Orthopaedic Aids*, Chris Dartnell (see p. 774).



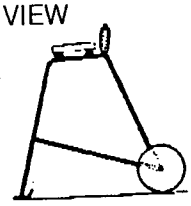
Cut and bend rod.



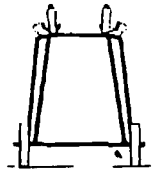
Assemble walker



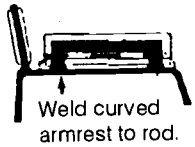
SIDE VIEW

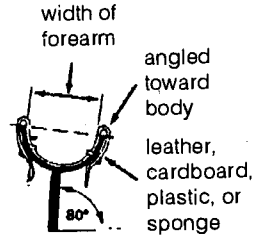


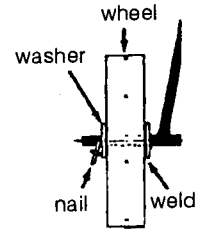
FRONT VIEW



ARMREST

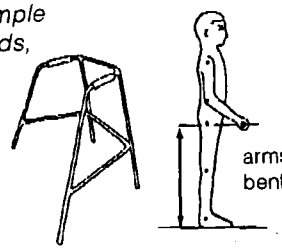






SIMPLE WALKER MADE FROM SOLID IRON ROD (RE-BAR)—WELDING REQUIRED

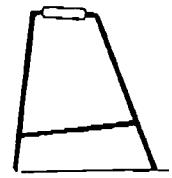
Design from *Simple Orthopaedic Aids*, Chris Dartnell (see p. 774).



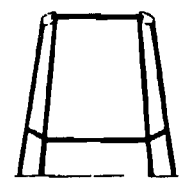
Cut and weld rod.



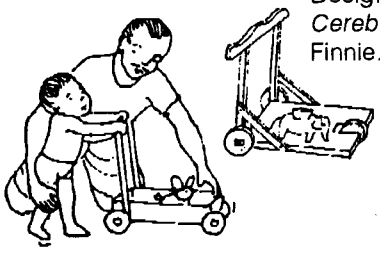
SIDE VIEW



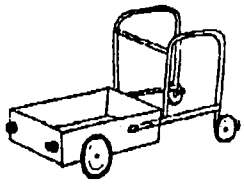
FRONT VIEW



CART WALKERS

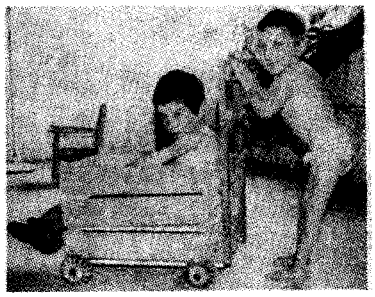


Design from *Handling the Young Cerebral Palsied Child at Home*, Finnie. (See p. 770.)



The added weight in the cart can help the child stand firmly–and makes learning to walk more fun.

As the child progresses, he can change his grip from the front bar to the side bars.



CP

Wheels on this cart walker are made from the round seed pods of a tree in Mexico, called Hava de San Ignacio.

ROLLER SEAT AND TRICYCLE WALKERS

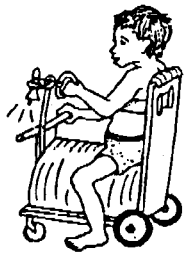


Useful for a child with cerebral palsy who 'bunny hops' (crawls pulling both legs forward together). Seat holds legs apart. The 'chimney' Helps child keep his arms up and apart.

Design from *Handling the Young Cerebral palsied Child at Home*, Finnie. (See p. 770.)



stable for the beginner

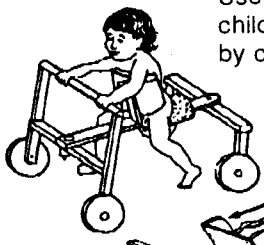


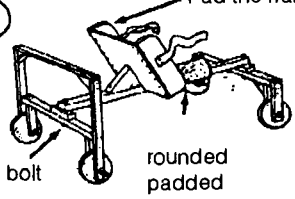


CP

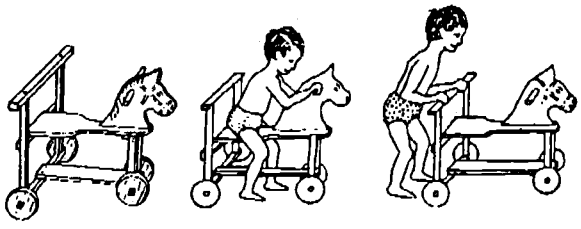
SPIDER WALKER

Useful for the small child severely affected by cerebral palsy.



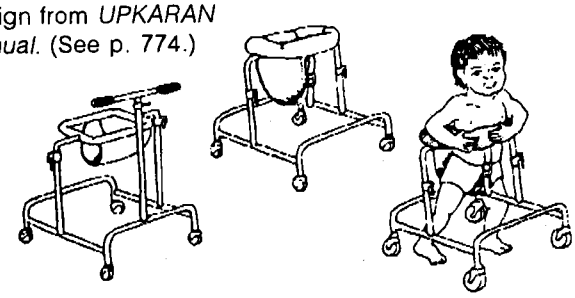


WALKERS FOR SITTING AND STANDING



SADDLE-TYPE WALKER

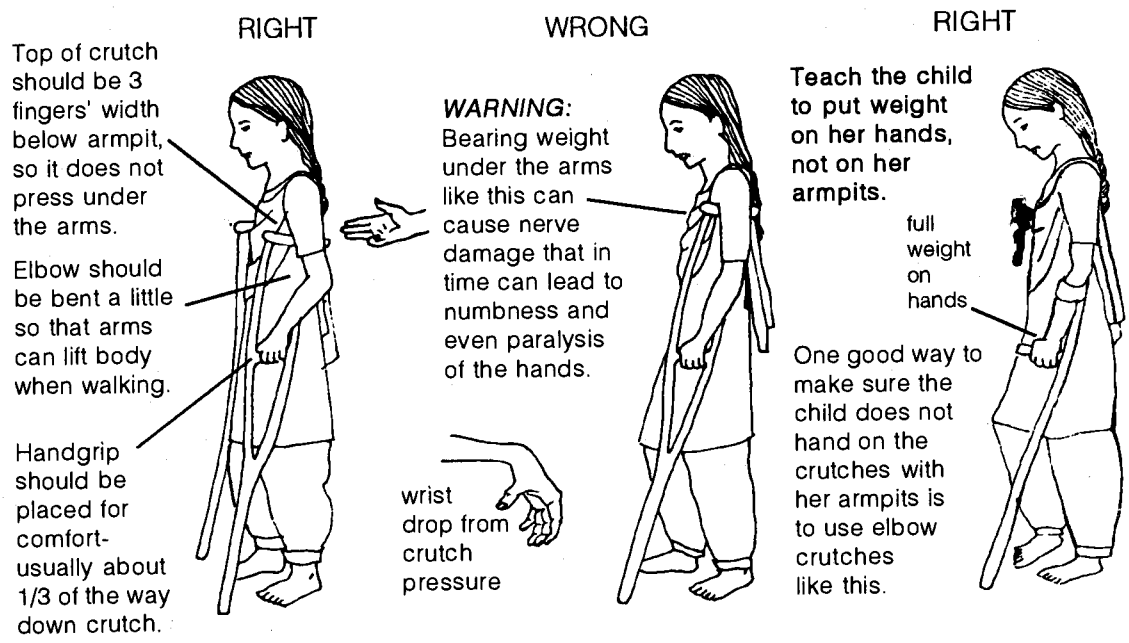
Design from *UPKARAN Manual*. (See p. 774.)



CAUTION: Sitting walkers should usually be used, if at all, as an early and temporary step toward walking. With them, the child does not learn to balance well and the hips are often at an angle which can form ***contractures*** (see Chapter 8, p. 96).

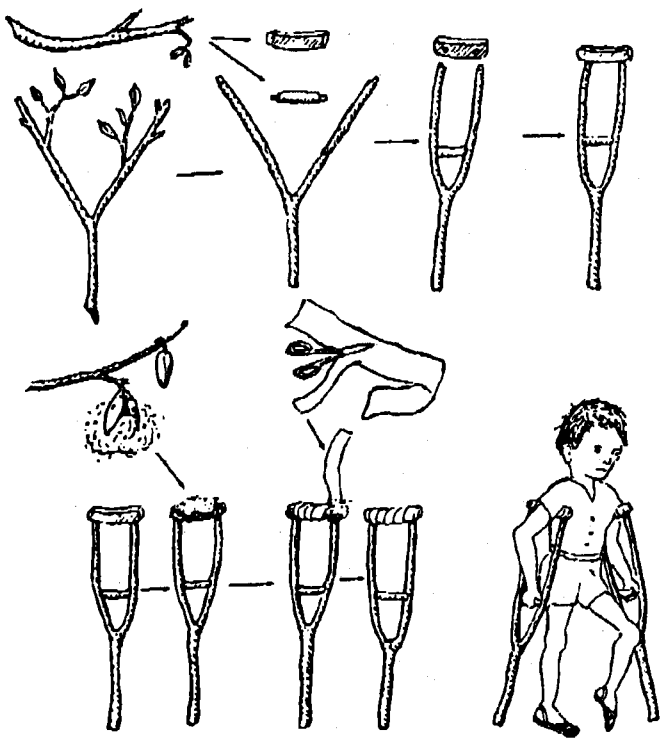
Crutches

MEASUREMENTS FOR UNDERARM CRUTCH

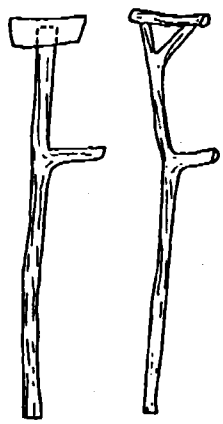


There are many designs for underarm crutches. Here we show a few.

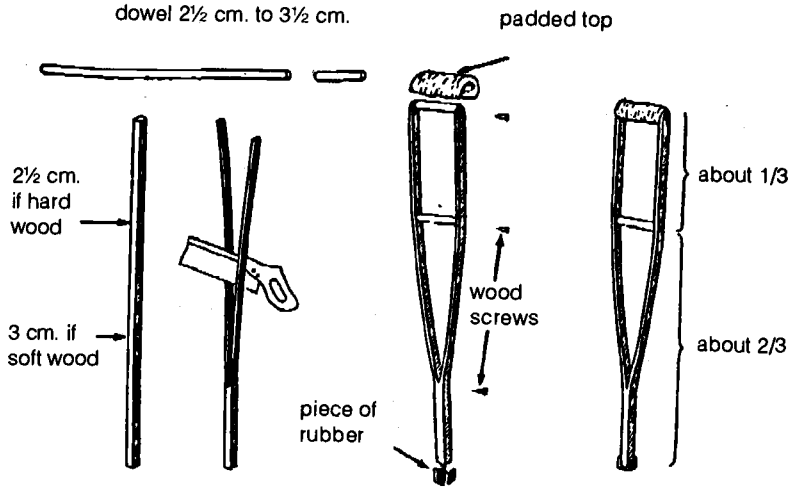
CRUTCHES FROM TREE BRANCHES, padded with wild kapok or cotton



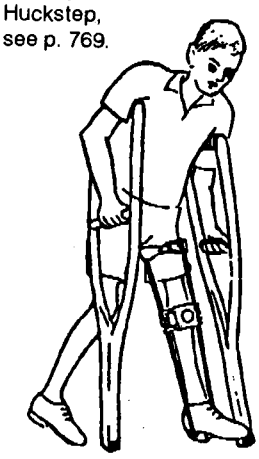
These single support designs using tree branches are not as strong as the double support design shown at left.



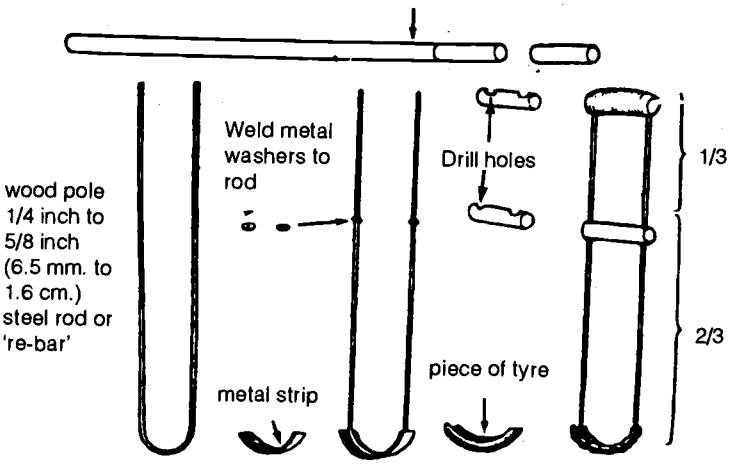
WOODEN CRUTCHES



Design from *Poliomyelitis*, Huckstep, see p. 769.



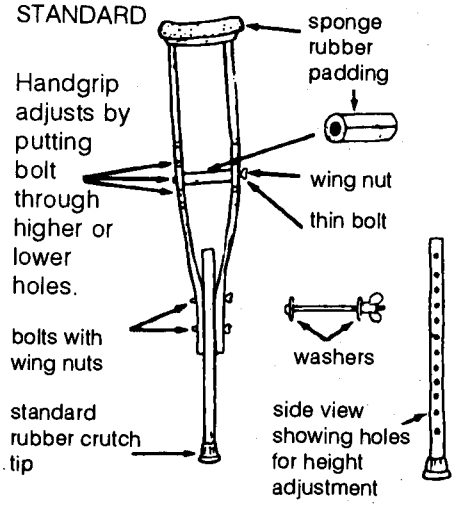
METAL CRUTCH



From *Poliomyelitis*, Huckstep. see p. 769



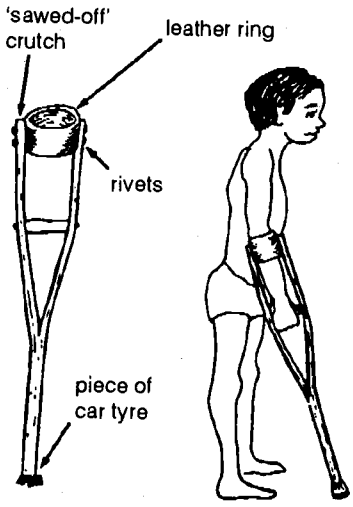
ADJUSTABLE WOOD CRUTCH



LEATHER RING ELBOW CRUTCH

These crutches are easy to make and work well for children who have strong arms and hands.

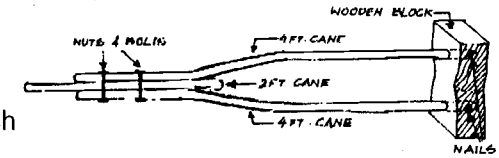
A disadvantage is that if a child falls he may have trouble getting his arms out quickly.



CANE CRUTCHES

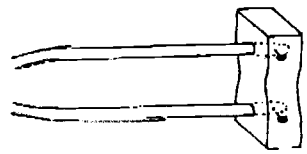
Crutches can be made from mature and strong cane. These crutches are being made at the Jalpaiguri Welfare Organisation in West Bengal.

They are as strong and last as long as crutches made from wood and also cost very little. They are easy to make and require only simple tools. They can be made in less than three hours.



Materials Required

2 pieces of hard cane - 4 feet (1.2 metres) each
1 piece of hard cane - 2 feet (0.6 metres)
1 piece of hard cane - 3-1/2 inches (9 cm)
1 piece of soft wood 8 inches x 2-1/2 inches x 2 inches (20 cm x 5 cm x 5 cm)
Cotton or foam
Nails
Nuts and bolts

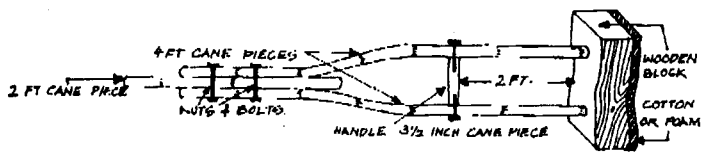


How to Make the Crutch

- Take a 8 inch x 2-1/2 inch piece of wood and make two holes of 1 inch (2 cm) diameter in the wood
- Heat all of the cane pieces using a blow lamp or simple oven. The idea is not to burn them but to make the canes harder and stronger.
- Take the two 4 foot cane pieces and insert one end of each piece into the hole of the wooden block. Nail them into place to secure them.



- Strap the 2 foot cane between the other ends of the 4 foot canes. This should be secured with nuts and bolts. Make the holes by drilling through the three pieces of cane. If you need to adjust the height of the crutch, you should do it by moving the position of the 2 foot cane, so making the overall height of the crutch taller or shorter as required.



- Place the 3 1/2 inch cane piece at a distance of 2 feet (0.6m) from the wooden block and secure it with two nails. Finally cover the wooden block with cotton or foam or some other padding to make the crutch more comfortable to rest under the arm. Again secure this padding with nails.
- Check that all of the nails and bolts are secure and that none of them are sticking out so that they could cut anybody. Then the crutch is ready to be used.

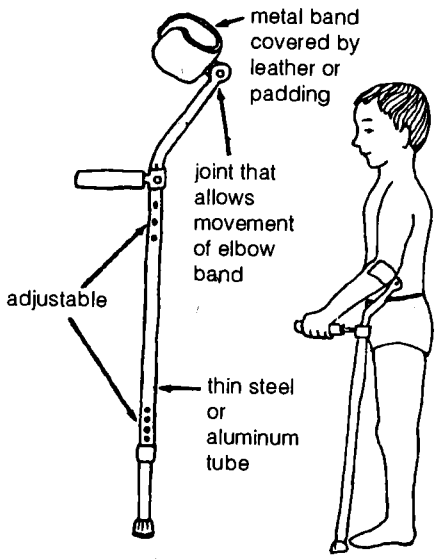
> ***Note:*** The height of the crutch will depend on the height of the person who is going to use it. The person should be able to use the crutch under their arm as a support.
>
> Select hard and good quality cane, 1 inch (2cm) in diameter. The Jalpaiguri Welfare Organisation recommends a variety of cane known as 'Garal'.

AdaPted from AGEWAYS 20

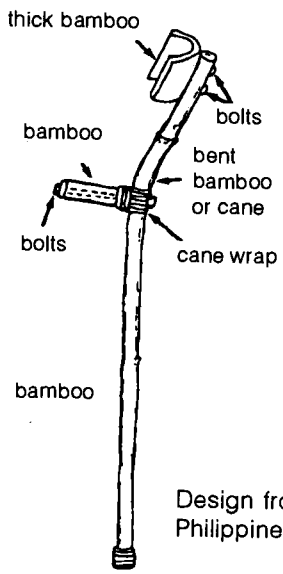
OTHER ELBOW CRUTCHES

With these open elbow-ring crutches, the child can easily get his arms out if he falls.

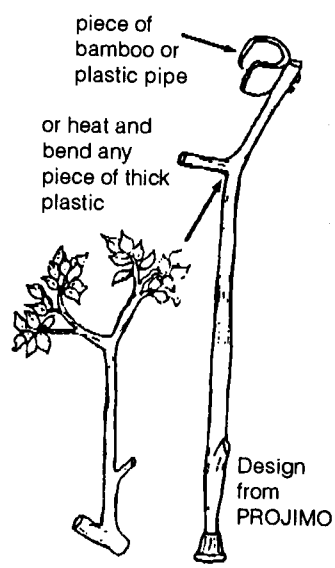
STANDARD ADJUSTABLE



USING LOCAL RESOURCES



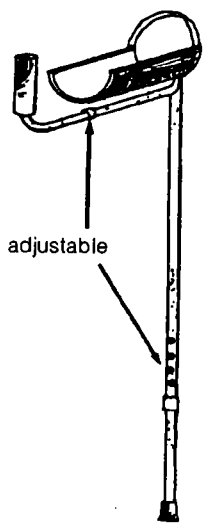
Design from Philippines



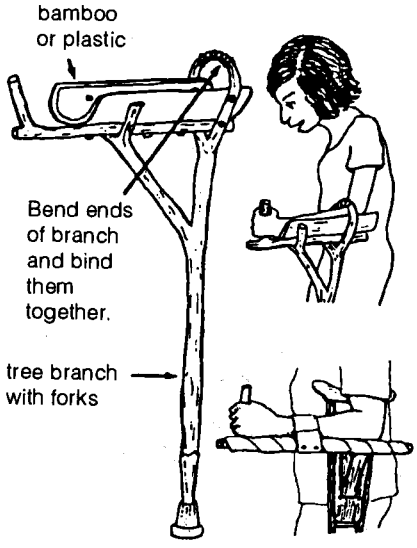
Design from PROJIMO

Gutter crutch ('arthritis crutch')
For children who, due to elbow pain or stiffness, cannot use straight-arm crutches.

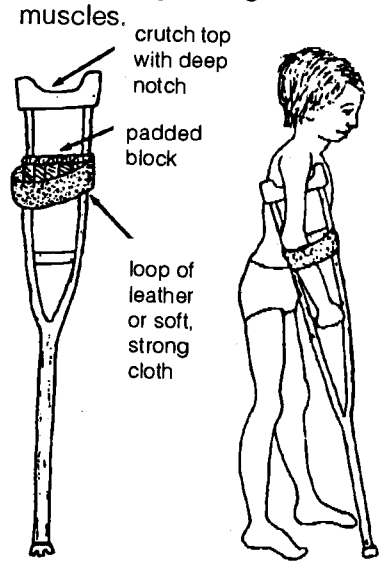
STANDARD



USING LOCAL RESOURCES



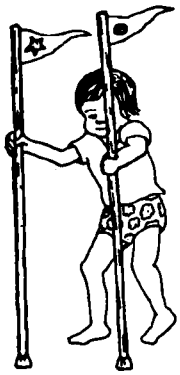
Crutch for a child with weak elbow-straightening muscles.



These are only examples. Once you get the idea, you can invent your own. A lot of experimentation is often needed to adapt crutches for children with severe arthritis.

Cane and walking sticks

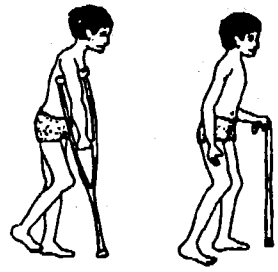
Straight poles can help a child with balance problems.



CAUTION: Use poles that are taller than child so if she fails they will not poke her eyes.

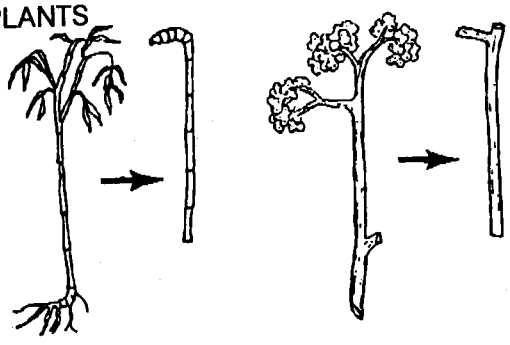
Canes. Simple canes provide some balance and support, but the child has to use the walking muscles in both legs



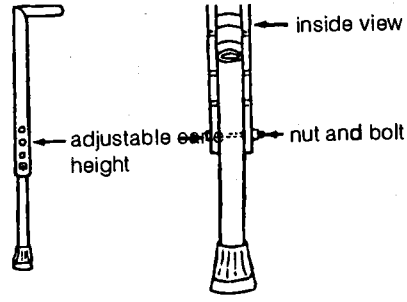


For the child who needs to strengthen a weak or painful leg, a cane makes him use his leg. A crutch lets him avoid using his leg, so the muscles that bend his leg get stronger, rather than the ones that straighten it.
(See p. 638)

CANE CUTS FROM FOREST PLANTS

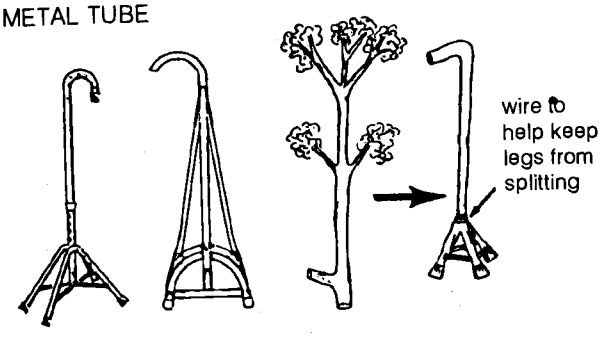


ADJUSTABLE METAL TUBE CANE

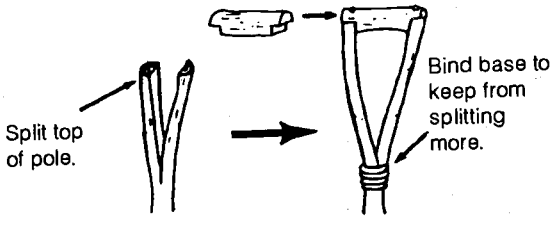


3 OR 4 FOOTED CANE-FOR GREATER STABILITY

STANDARD METAL TUBE

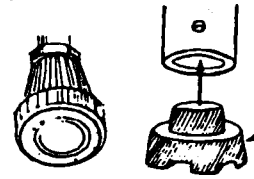


ALTERNATIVE HANDGRIP



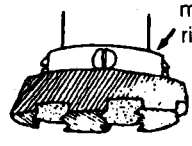
Rubber tip made from car tyre for metal tube or bamboo crutch or cane

STANDARD CRUTCH AND CANE TIP



With a sharp knife or grinder, cut a plug of car tyre in this shape.

Force it into the tube and fasten it with a screw metal ring.

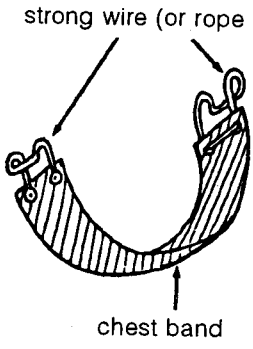


For walking in **sandy places,** make crutch and cane tips extra wide.

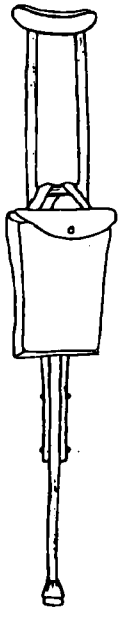
Adaptations of walking aids for carrying things and for work

CRUTCH SLING
to free hands
for work

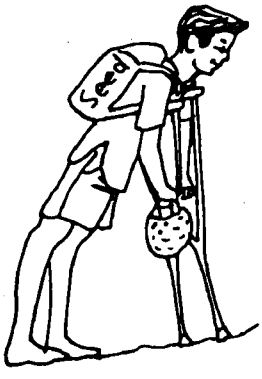


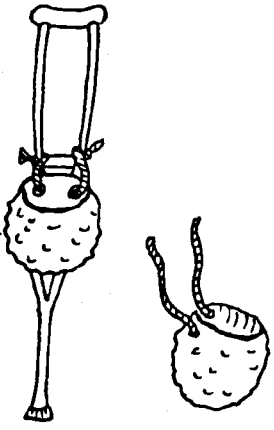


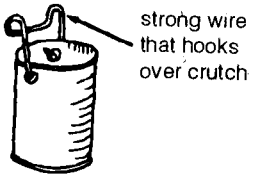
LEATHER OR
CLOTH
POUCH



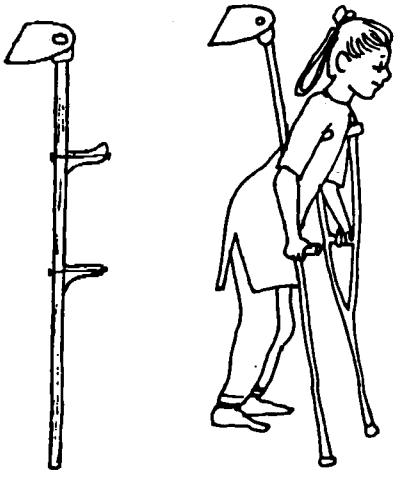
BACK PACK

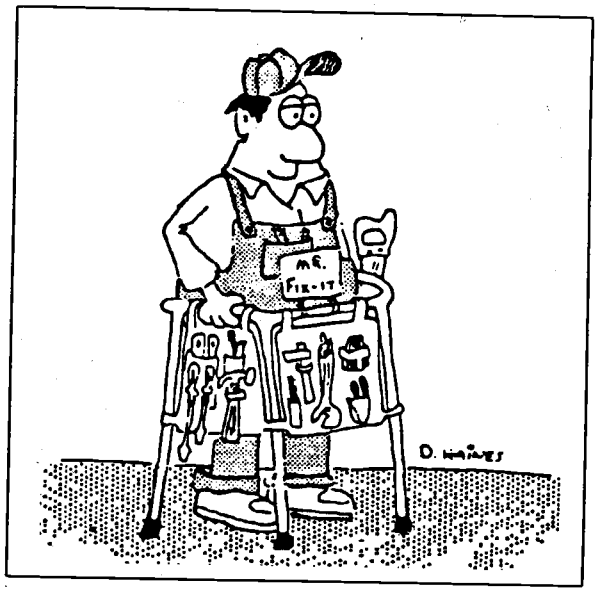






HOE ADAPTED AS CRUTCH





Reprinted from Accent on Living, 1984

NOTES

CHAPTER 65

Decisions about Special Seats and Wheelchairs

In this chapter we look at the things you will need to consider when buying or building a special seat or wheelchair, to best meet the needs of a child. Adaptations of seats and wheelchairs for special positioning needs are discussed in Chapter 66. Designs for building 6 basic wheelchairs are in Chapter 67.

Meeting the needs of the individual child, family, and community

Most children who need a wheelchair or special seat have severe weakness in parts of their bodies, or *muscles* that pull them into awkward or deforming positions. Seating should, as much as possible, keep these children in **healthy and useful** positions. It must **provide support**, but also **allow them enough freedom** to move, explore, and develop greater control ot their bodies. For example:

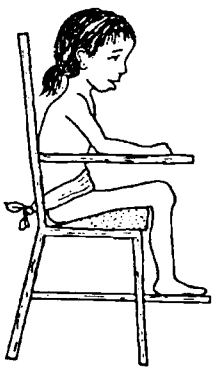
1. A child who is 'floppy' and slow to develop ability to sit.



2. may at first need a seat with straps and supports to hold her up.



3. As she develops better head control and then body control, the supports can be removed little by little.



4. until finally- if possible- she is able to sit anywhere, with little or no special supports. Now low back support is all she needs.



CAUTION: If a child needs to be supported as much as the one in the second picture, do not keep her strapped in her seat for long. She also needs periods of free movement and exercise to develop more independent head and body control. Keeping her strapped in for too long, or providing too much support after she has begun to gain more control, may actually slow down her progress. Seating needs to be changed and supports reduced as the child develops.

Also, children who do not feel in their buttocks need frequent position changes and 'lifting' (see p. 232), and special cushions (see p. 234).

Special seats and wheelchairs need to be adapted not only to the individual child, **but also to the particular family, local customs, and community situation.** For example:

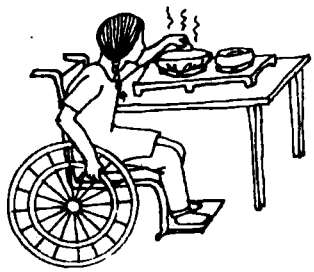
A **'high chair'** lets the child join the family that eats at a table.



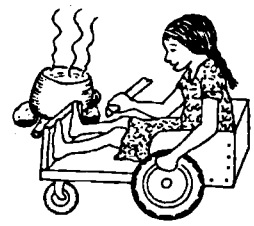
A **'low chair'** lets the child fit in where the family eats at ground level.



Also, a **'high' wheelchair** may be helpful where cooking and other activities are done high up.



But a low **'wheelboard' or 'trolley'** may be better where cooking and other activities are done at ground level.

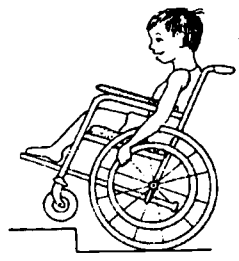


It is also important to consider the type of ground surface on which a wheelchair will be used.

Where land is flat and fairly smooth, and entrance into houses is level, a chair with a small wheel at the rear may work well and be less costly to make.



But where there are curbs, steps, rocks, or other obstacles, a chair with small wheels at the front works better.



To jump over obstacles, the child can learn to do a 'wheely' (tilt the chair back with the front wheels in the air)

On rough, sandy surfaces wide back tires and relatively large, wide front casters makid moving about much easier.

Narrow back tires and small front wheels allow for faster travel on hard smooth roads but are useless on rough, sandy roads



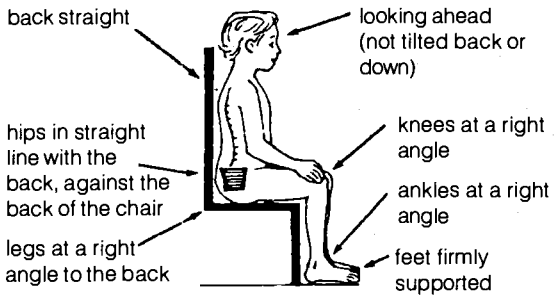
Wide tires, like the wide feet of a camel, help in sandy places.

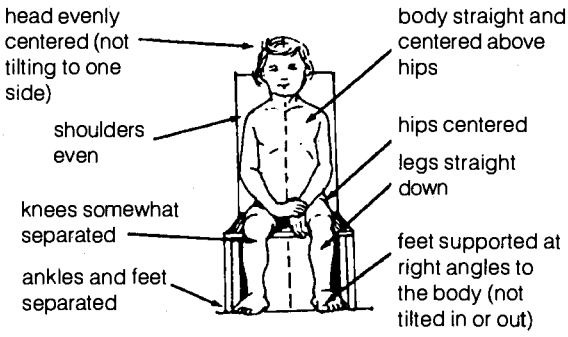
Having the right wheelchair for the local situation frees the child to move about more easily in the community.

Healthy, comfortable, and functional positions

Whether or not a chair has wheels, **the position in which it allows a child to sit is very important.** (See Chapter 66.)

For most children, the chair should help them to sit more or less like this:





CAUTION: **The seat should be wide enough to allow some free movement and narrow enough to give needed support** (see Measurements, p. 728).

Common seating problems and possible solutions

Problem : Hips tilt back



In children with spastic cerebral palsy the hips often stiffen backward. This triggers spasms that straighten the legs and cause other muscle tightness with loss of control.



Also, children with weak hips or back, from spinal cord injury, spina bitida. or severe polio, often sit slumped with their hips tilted back and the back severely curved. This can lead permanent deformity.

CP

One of the most common causes of backward tilting hips is a chair like this one that is too big for the child.

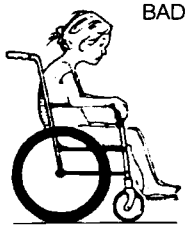
Other causes of backward tilt and bad position are:

a chair back that tilts far back

and a cloth back that sags.

These let the child lean back and cause the hips to to slip forward.

BAD



Also, footrests that are far forward so that knees do not bend enough can increase spasticity that tilts hips back.

A good position can often be gained through:

A fairly stiff, upright back at a right angle to the seat,

a chair that fits the child so that his hips reach the chair back,

GOOD



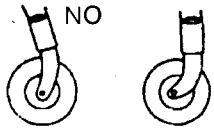
the knees at right angles, and **feet firmly supported.**

BETTER



Most children, and especially a child who tends to fall forward in his seat, will sit better and more comfortably if the whole chair tilts back a little. But be sure to keep right angles at hips, knees, and ankles.

To tilt the chair back, the rear wheel mount can be moved higher up. You may also need to move the wheel mount **back** farther to keep the chair from falling backward with going uphill. Be sure the front caster barrel is still straight up or making turns will be harder.



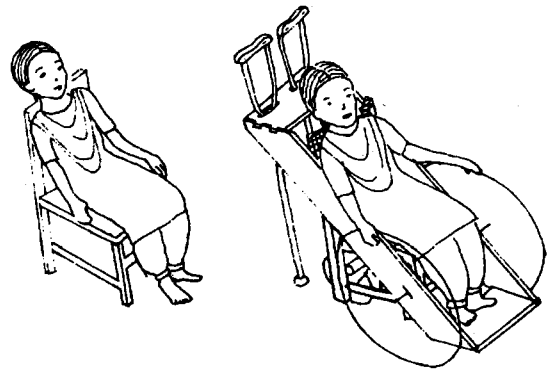
Keeping cost down and quality up

For many families, a wheelchair can be a great or even impossible expense. There are many ways to keep costs down. But be careful. Some low-cost choices may make the chair too clumsy, weak, or unsafe. Other low-cost choices may actually increase the chair's usefulness and life. For example, a very useful, long-lasting wheelchair can be made of wood -or from a cheap wooden chair. Even wheels made of wood (if made well) may work well and last a long time. But, making the hubs or bearings of wood usually leads to trouble. Standard wheelchair wheel bearings are very expensive. However, you can often get strong, high-quality, used metal bearings free or very cheap at electrical appliance repair shops or auto repair shops.

Factory–made or homemade wheelchairs ?

Often you can save money by making your own wheelchair or by asking a local craftsperson to make one. Also, a homemade chair design can be more easily adapted to your child's particular needs.

On the next pages we give information that may help you decide about different wheelchairs and effective low-cost ways to make them.



You can make a tairly eftective low-cost wheelchair by attaching bicycle wheels or wooden wheels to an ordinary wooden chair. Also, it is easier to attach special aids or supports to a wooden chair than to a metal chair. This design is adapted from AHRTAG's booklet, "Personal Transport for Disabled People" (see p, 730).



Any wheelchair is better than none-but sometimes not much better. Look for low-cost alternatives that make a chair better-not worse.

REMEMBER: A wheelchair needs to satisty the rider–not just the maker. Before (and after) buying or making a chair, think carefully about the different features that will help it best meet the needs of the particular child and family.

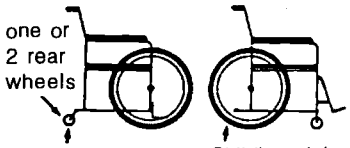
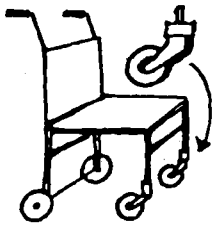
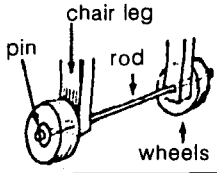
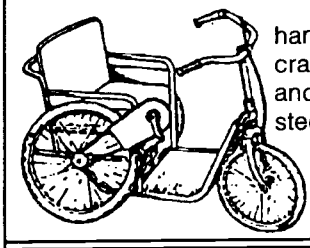
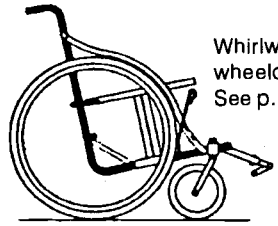
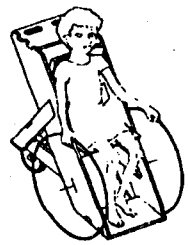
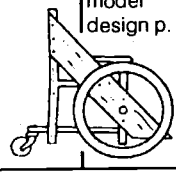
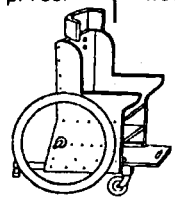
When buying or making a wheelchair (or any other aids), consider:

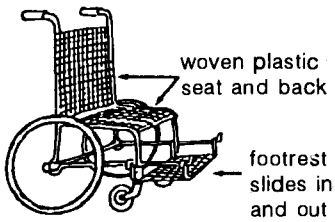
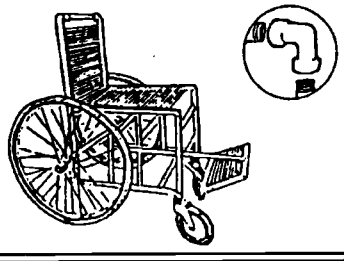
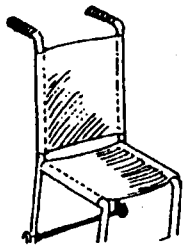
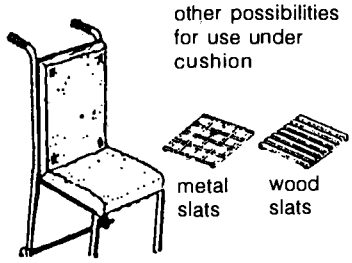
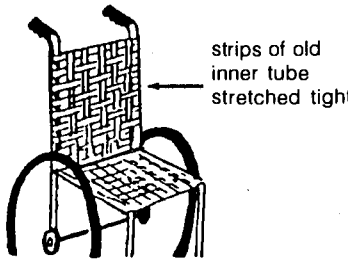


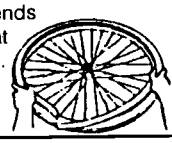
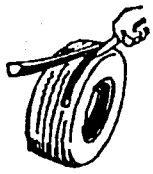
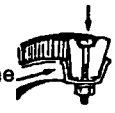
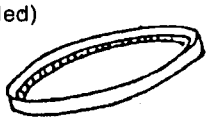
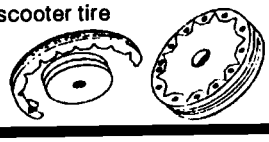
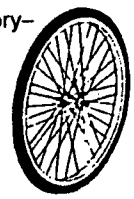
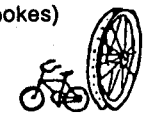
- **Cost.** Keep **cost low** but **quality high** enough to meet the child's needs (see p. 718).
- **How long will the chair last?** The longer the better, unless it is only for temporary use.
- **How easy and quick is it to make?** The easier and quicker the better, as long as it meets your needs.
- **Availability of materials.** Make use of local low-cost, good-quality resources (local wood, cheap metal, used bearings, bike parts, etc.).
- **What tools and skills are needed to make it?** If welding equipment or skills are not locally available, a wooden chair may be a more practical choice.
- **How easy will it be to adjust or repair?** Wood chairs that are bolted together are often the easiest to adjust or add special supports to.
- **Weight.** The lighter the better, while making sure it is strong enough.
- **Strength.** Heavier persons need stronger chairs and stronger axles. (A small child's chair may be supported by a bicycle axle attached on one side only. A bigger child needs the axle to be supported on both sides, or a stronger axle. See p. 724 and 743.)
- **Width and length.** The narrower and shorter the better while meeting the child's needs (but not so short that it tips over easily).
- **How easily can it be moved** – by tne child sittirig in it or by someone behind? **How easily can it be tilted back** to go over rough spots? **Lifted** up stairs? **Transported?** (Does it need to **fold** to take up less space?)
- **How well is it adapted to the particular child's wants and needs?** Is it comfortable? Does it allow the child to sit in a healthy position?
- **Fit and growth factor.** How well does it fit the child now? How long will it continue to fit her? Can it be adjusted to fit her as she grows?
- **How well is it adapted to living situations, the home, local customs,** width of **doorways,** surface of **floors** and **roads,** curbs and other barriers?
- **Appearance.** Is the chair attractive? Does the child take pride in it? Do other children want to ride it?

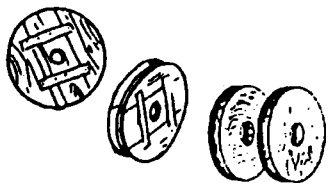
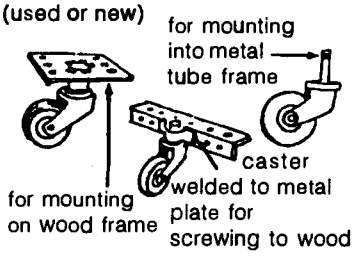
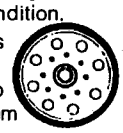
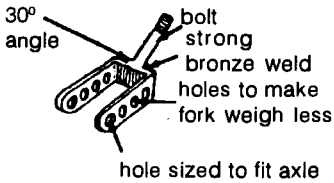
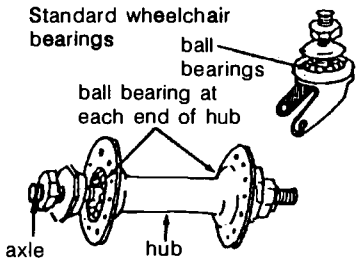
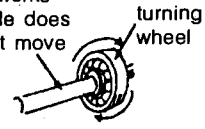
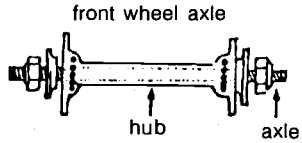
In considering choices for the design, building materials, and special features of a wheelchair, be sure to carefully consider the above questions.

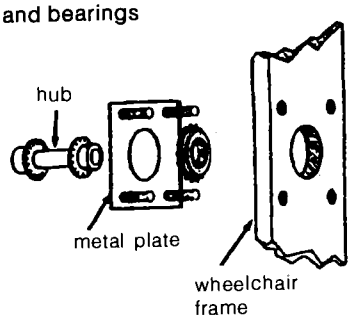
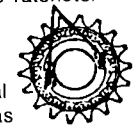
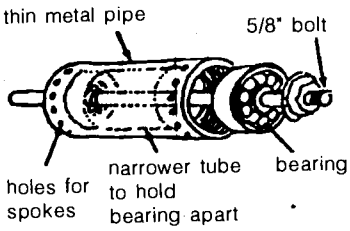
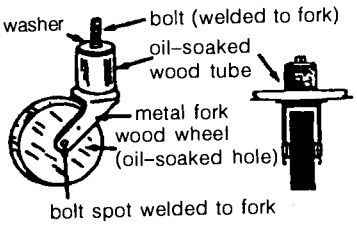
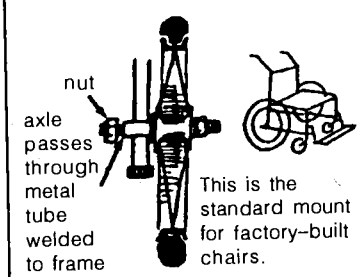
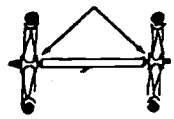
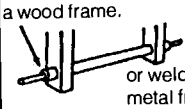
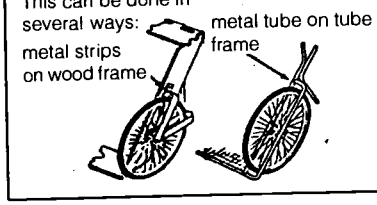
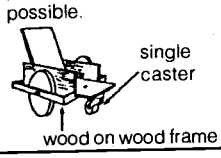
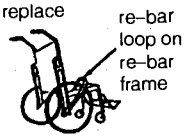
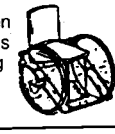
Design choices for wheelchairs

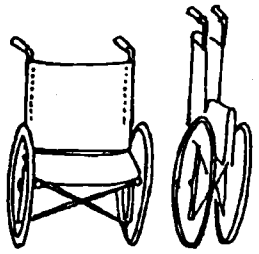
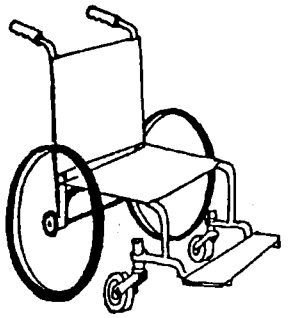
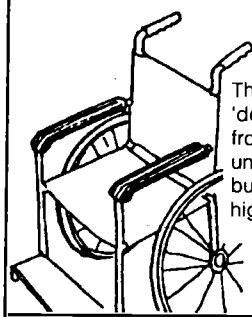
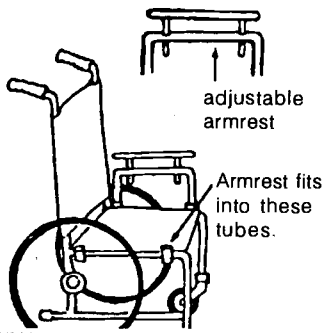
FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
WHEEL SIZE AND POSITION **2 big wheels** with 1 or 2 small caster wheels INDOOR OUTDOOR  one or 2 rear wheels rear wheel set back to avoid tipping backward one slopes Child's weight should be mostly over big wheels.	• Large wheels let rider push herself. • Small caster wheels allow easy turns (on cement, not sand). • For leg amputees, rear wheels must be moved back to prevent tipping over backward. 	• Child can move it herself if she has hand and arm control. • Large wheels go over rough surfaces easier.	• takes up more space • harder to get in and out of from the side (because wheels need to be higher than seat so that rider can push herself)
4 small wheels  casters for easier turning	Very simple temporary chairs can be made by putting 4 wheels on an ordinary wood chair.  chair leg pin rod wheels	• good only on smooth floors for a child who cannot push of help push his own chair • cheaper • takes up less space • easier to move child in and out of	• not good on rough surfaces • Child cannot move it herself. • creates dependency
3 big wheels  hand crank and steering	• You can use 3 bicycle wheels • Some models have removable front wheel so that chair can be easily changed to have small front wheels for use inside the home	• excellent for long distance and rough road travel • can be used by a person with strength in one hand only some riders have 2 chairs one like this for road travel, and a smaller one for home or work	• too big for use inside home • more costly • more difficult to make
BUILDING MATERIAL FOR FRAME **steel tube**  Whirlwind wheelchair See p. 750	• thin-walled electrical conduit tubing can be used - 5/8 inch to 1 inch diameter.  AHRTAG design see p. 730	A strong, long-lasting, fairly light chair can be made better and cheaper than most commercial chairs.	• requires welding skills, some design ability, and a fair amount of equipment • a good chair for a well-equipped rehabilitation center workshop to build, but not a family • builders need to be trained
Wood  AHRTAG model	For wood design details, see p. 743 and 748 and references on p. 730. wood chair model design p. 743  	• relatively cheap and easy to make- mostly wood,few or no welds • easy to adapt and to add special supports or tray tables plywood model design p. 748	• May not be as stable and long-lasting as other models (For tighter joints and more adaptability, use nuts and bolts instead of nails)

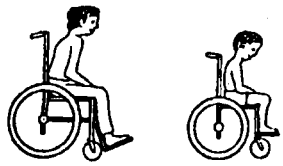
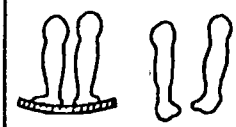
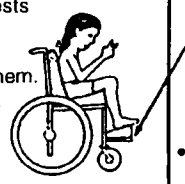
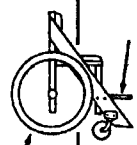
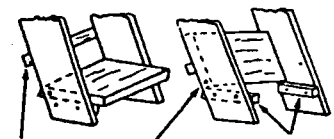
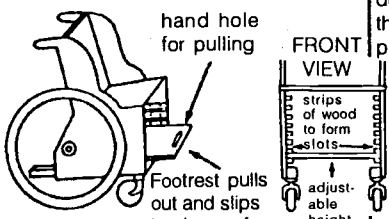
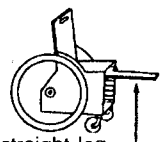
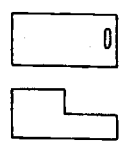
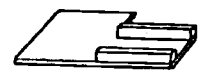
FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
Re-bar (metal reinforcing rod used to strengthen cement)  	Design can be the same as for metal tube chairs,. but it is easier to adapt because the re-bar is easy to bend.	• relatively cheap • easier to bend and weld than steel tubing • can have plastic woven seat and back (easy to clean) • especially good for small chairs	• A heavy person or rough treatment may bend it our of shape. • fairly heavy
PVC pipe (plastic water pipe) 	• Use 15 mm. PVC pipe. • Comes with joints so that is can be fitted together with a special glue • For details see reference p. 732.	• lightweight • can be built mostly by glueing pieces together	• costly materials (around $ 100 US) • Plastic tubing will in time sag or bend in the direction stress. Therefore it may be necessary to fiberglass the frame which adds to cost, work, and weight.
SEAT AND BACKS soft canvas or leather stretched between supports 	• For child who is likely to urinate or pass stool in the chair, use a cloth that is easy to wash. • Plastic-coated canvas makes cleaning easy but is hot and may irritate child's bottom. Best to use an absorbent washable pad over it.	• easiest seating and back design for folding wheelchairs • Adjustment to shape of butt gives comfort (but cushion is needed to protect against pressure sores). • Curving back may help keep child from falling sideways.	 • Soft,curving back lets child bend in an unhealthy position (see p. 717). • More chances of source development • hard to attach positioning aids • In children with spasticity or muscle imbalance, this may increase the risk of developing knock-knee contractures.
firm (but padded) back and seat  	• Use wood or thin plywood • Special designs allow a wood seat to swing up for folding	• Wood seat and back allow easy addition of supports and adaptations.  • Firm wood back and seat help child sit with back straight and knees apart (especially important for children with spasticity).	• may be less comfortable • without cushion may cause pressure sores in child with no feeling in his butt • heavier • difficult or impossible to fold the chair
Woven seat and back  	• Use natural basket fibers, reeds, or rattan. • or use plastic webbing. • or use tightly stretched strips of car inner tube.	• An open weave is cooler is hot weather. • Plastic or rubber woven seats can be easily washed. Can be used as a chair to bathe in.	• must be kept stretched tight; not useful on folding chairs • may not last long if materials is not strong • same sag problems as with canvas or leather

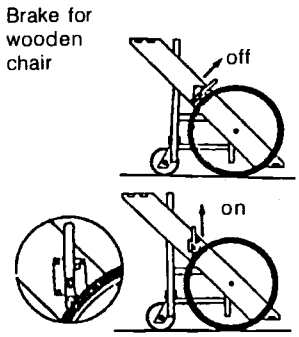
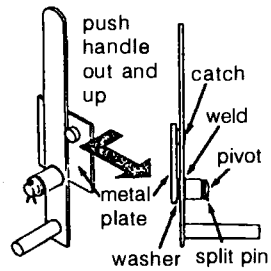
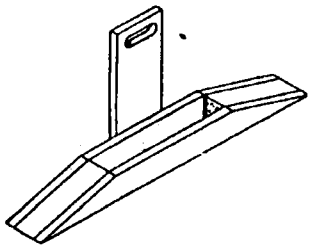
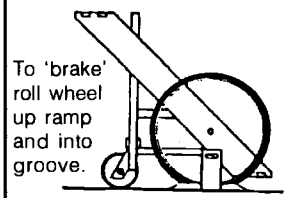
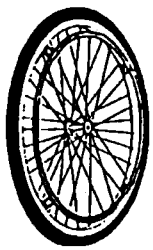
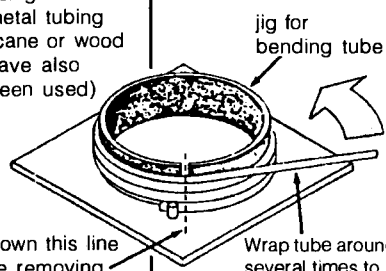
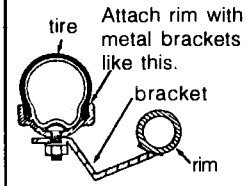
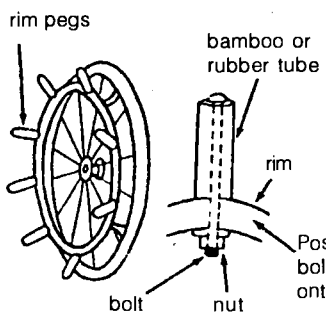
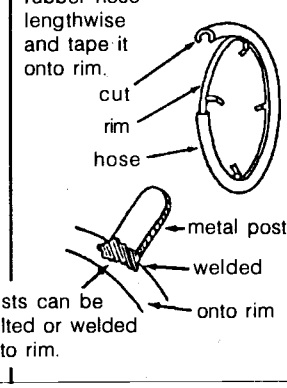
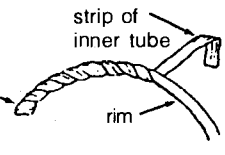
FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
TIRES **Pump–up with air 'balloon' tires** 	• Bicycle tires and tubes work well for the large wheels – 20 inch (51 cm.), 24 inch (61 cm.), or 26 inch (66 cm.), **wide or narrow.** Puncture–proof inner liners may be available.	• **softer ride** • easy to replace • **wide** tires good for sand and rough ground • **narrow** tires better on smooth, paved roads	• **Puncture** (hole in tire) may occur–especially on rough roads. • more costly than some other tires. • wears out sooner than solid tires
Solid tires (standard wheelchair wheels) 	Buy from wheelchair supply center to fit diameter and width of rim.	• no flat tires • good for speed on very smooth surfaces	• costly • hard to replace • very hard, bumpy ride on rough surfaces • very narrow–sinks into sand
Rubber hose inside bicycle tire 	• Overlap ends and cut at 45° angle. • Fit hose into tire. 	• no flat fires • softer ride than with solid tire • cheap	• Flattening of tire where it touches ground means if moves slower, and is harder to push
Thin strip of old car tire 	• Cut strip in wedge shape to fit rim. • Wire ends together. 	• no cost • long–lasting Sink bold head. Wire ends together. and/or bold the ends. 	• bumpy ride • difficult to fit well on rim and to fasten ends firmly.
Large machinery fanbelt (discarded) 	• Use old power belts or fan belts from industrial machinery or tractors. Cut to fit and wire ends together.	• no cost • long–lasting • wedged to fit wedge rim	• bumpy ride • difficult to fit • may be hard to find at the right width
Piece of old bicycle or scooter tire 	• used for middle–sized or small **wood wheels** • Notch edges, glue, and nail to wheel.	• cheap • if heavy tire is used it may last a long time. • Protects edge of wood wheel.	• hard, bumpy ride (but softer than on wood wheel alone) • may tear off
BIG WHEELS **Standard factory–made wheelchair wheels** 	• Buy to fit chair • available from wheelchair dealers • 24 inch (61 cm.) or 26 inch (66 cm.) rims for adults • 20 inch (51 cm) rims for small children (may be hard to find)	• little work needed (if they are bought to fit standard hubs) • May come fitted with hand push rim.	• costly • may be hard to find • wide–wheeled models often not available • may not hold up on rough ground • poor quality bearings
Bicycle wheels (rims and spokes) 	• For children, standard thickness spokes may be enough. • For large persons, heavy–duty spokes, may be needed.	• less costly than standard wheelchair wheels • available in different sizes and width	• Putting on and lining up spokes takes time and skill • axles weak (but stronger ones can be adapted)
Bicycle rims with wooden spokes. 	• notched wood cross–pieces on a triangular wood base can be greased and used as the hub	• no need to know how to fit spokes • works with wood hun	• Rim may easily get bent–especially on rough roads. • hard to line up evenly • Hub wears out easily

FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
Wood wheels–big or small 	• Use boards or plywood • To avoid splitting, screw and glue 2 layers together with grain running in opposite directions. • Cut notch in rim to hold solid tire. 	• relatively cheap • little skill required–mostly carpentry • works with wood axles • heavy–duty bearing can be added	• often heavy • may not hold up long–especially in wet climate or mud (keeping wood oilsoacked helps them last. Use old engine oil.)
CASTERS AND WHEELS (Caster means that the wheel can swing in different directions for making turns.) **Standard wheelchair caster wheels** 	• Casters come with hard or balloon tires in many sizes, weights. styles, and prices. If possible, get (or make) casters with ball bearings.	• little work to attach–especially if standard mount and bearings are used	• usually very costly • may not be locally available
Casters from other (non–wheelchair) equipment (used or new) 	• Use 3 inch to 6 inch wheels. • larger, wider wheels for rough ground • Be sure bearings are strong enough and in good condition. • Drill holes in rubber wheels to make them weigh less 	• less costly (especially if not new) • often full wheel and caster bearing come with them	• Poor quality casters make wheelchair much harder and more awkward to use • Hard–rubber casters make a bumpy ride • Some used casters are too weak.
Bent and welded steel caster forks 	• Choose bolt width to fit bearings • A bent steel tube can be used instead of metal band	• less costly than factory–made casters • strong (if well made)	• needs special equipment (bending jig) and welding skills
HUBS, BEARINGS, AND AXLES Standard wheelchair bearings 	• A standard wheelchair uses 12 bearing 2 for each wheel axle and 2 for each upright caster bearing • How a ball bearing works 	• These bearings come as part of standard wheelchair hubs and wheels. • Most factory–built wheelchairs have unusual sized axles and therefore must be fit with special wheelchair bearings.	• Bearings on most factory–built chairs are costly, of poor quality, and wear out quickly. • Unusual hub size makes it hard to replace commercial wheelchair bearings with other standard machine bearings
bicycle bearing and axles 	For mounting alternatives see wheelchair design p 724 and 743. Also, see the AHRTAG Manual (see p. 730)	• cheap–especially if old bicycles are used • easy to get • can be used with complete bicycle wheels	• Axle is too weak to be supported by one end only (except in a small child's wheelchair)

FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
Rear bicycle wheel axle and bearings  	• First take free-wheel mechanism apart and remove ratchets. • Then attach hub to a metal plate as shown and spot weld it.  • Other methods for one-end axle support are in the AHRTAG Manual (see p. 730).	• Allows axles to be attached by one end only.	• Needs fairly skilled work and welding. • heavy
Used machinery bearings  	• Find used high-speed bearing of the size shown (or near the size). *Vokswagen* alternator bearings and certain power tool size). Vokswagen alternator bearings and certain power tool bearings work well. • Use 5/8 inch steel bolts for axle. Fore details. see p. 730, 750, and 751.	• no need to adjust, grease, or clean • usually free or very cheap • In wheelchairs they will last a very long time. • If done well, results commercial hubs and bearings.	• very careful exact work needed for good results
Wood bearing  	• Use a hard wood that will not split. • Soak wood in old motor oil. • For more ideas and details on wood bearings, see AHRTAG Manual p. 730.	• cheap and fairly easy to make	• tends to wear out, wobble, or crack quickly unless very well made: not as smooth or easy to ride as with ball bearings.
SUPPORT OF AXLES **Axle supported on one side only**  	• Strong steel axles are needed for support at one side only. Axle should be at least 5/8 inch thick for a larger person. • For a very small child bicycle axles can be supported by one side only. One way is to weld bicycle axles to a thin metal pipe. 	• Not as wide or heavy as the chair with 2-side support. • easier for user to get a full-length push with hands and arms • narrow size important for doorways and transporting Pass pipe through a wood frame.  	• For adults and large children, standard bicycle axles are too weak for one-side support. • Even for smaller children, bicycle axles are weak, and rough use can bend them. Put a sign on chair FOR SMALL CHILDREN ONLY
Axle supported on both sides This can be done in several ways:  	• Place outer bar of axle support so that it allows as much room for hand pushing by the ride as possible.  	• 2-sided support allows use of standard bicycle wheels and axles. • easy to build and replace  	• chair wider, more difficult to get through narrow doors and spaces: more difficult to transport • wheel supports get in the way of hands when user moves by pushing wheels. • heavy 

FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
TO FOLD OR NOT TO FOLD **A typical folding chair** 	• folding mechanism usually with 2 scissoring flexible cross pieces and cloth or leather seat • For details of a make-it-yourself model, see p. 750.	**Folding:** • narrow when folded for easier transport or storage • smoother ride due to flexibility **Non-folding:** • cheaper and lighter • easier to make • more adaptable • often stronger	**Folding:** • heavier • harder to make • more costly • less adaptable **Non-folding:** • Transport in cars and buses more difficult. Consider how much this will affect the child's ability to go where she wants. • stiff ride
ARMRESTS **No armrests** 	*Note:* Many chairs are built so that armrests are part of the main structure and strength of the chair. The armrests cannot be easily removed, even though this might benefit the child. Carefully consider the child's need for armrests before buying or making a chair.	• Many children with strong arms and trunk control prefer a chair with no armrests and a very low back support • Moving by pushing the wheels is easier. • less weight • Getting off and on from the side is easier–especially important when legs are completely paralyzed and when arms are also weak.	• Many small children need armrests for stability for positioning, or for comfort
Fixed armrests  The so-called 'desk arm' lets front of chair fit under a table–but is often too high or too short.  table	• Armrest height and length should be determined for each child and her needs • For measurements, see p. 728.	• especially helpful if child cannot use legs to get out of chair • They can help child to sit in a better position and be more comfortable • They can sometimes be used for attaching a removable	• They get in the way for pushing wheels and for getting off chair to the side • For many children, fixed armrests get in the way more than they help. • It arm rets are too low the child will stump forward. He may find it difficult to breath. • Arm rets that are too high hinder elbow movement. The child find it difficult to reach the wheels.
removable armrests  adjustable armrest Armrest fits into these tubes.	• In folding chairs. armrest attachments must be places so they do not get in the way of folding.'  child transferring from a chair on a board–one armrest removed	• Provides arm support when needed, yet can easily be removed for travel and transfer.	• requires more work, materials, and exact fittings • add slightly to weight • Separate armrests may get lost. • Wider the seat with by about 2 inch

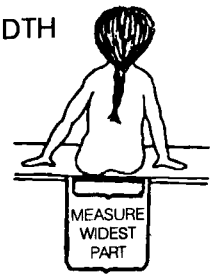
FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
FOOTREST Positions In adult chairs, footrest often angle legs forward to leave room for casters. For a small child, often footrests can position legs straight down. This is important in many cases (see p. 717).  A larger child may need to sit on cushions so that his feet are above the casters.	• Footrest should keep the knees and ankles at right angles and the legs slightly separated.  • It should usually not twit them or force them together. 	• Good positioning and support of the feet help the whole body to stay in a better position. A footrest like this, may help feet like these. 	• A footrest that keeps the leg at right angles may cause or increase knee contractures in some children. Children should not stay sitting too long and should do daily exercises to stretch their legs, feet, and hips.  To prevent or correct contractures, one or both legs may need to be kept as straight as they will go.
Fixed position footrests The height of the rests should be carefully measured to fit the child who will use them. (For measurements, see p. 728.)   *REMEMBER:* Cushions or seating adaptations will change the height needed for the footrests.	• If the footrest is too low, blocks can be placed on it to make it higher. They can be removed as the child grows. • However, fixed footrests that are too high are more difficult to correct. So it is better if they are too low. 	• easiest to build • For a small child who can easily be lifted in and out of the chair, they are fine. • If footrest are screwed or bolted onto a wooden wheelchair, their position can easily be changed as the child grows.	• They often get in the way when the child gets in or out of the chair, or in the way of the person lifting a larger child. (See other methods below.)
Removable or swing-away footrest wood chair swing-away footrest  back-stop for feet pin on which footrest swings stops	There are many designs. Here we show one for the wood chair shown above and one designed for a metal chair. Other designs for sliding of swing-away footrests are on pages 744. and 750. metal chair footrest See p. 750.  swing up	• They make it easier to get in and out of chair. • The best footrests are those the child can easily move out of the way herself. 	• Removable footrests may get lost • more work to make them • Unless well-made, they may be less stable than fixed footrests.
Adjustable footrests  hand hole for pulling FRONT VIEW strips of wood to form slots adjust-able height Footrest pulls out and slips back out of way. Also serves as storage shelf.	There are many designs. Here is one of the Simplest, for a plywood chair.  For straight leg sitting, a longer board fits into high slots.	• very adaptable • easy to make • can support a casted leg  leg board for both legs for one leg	• A cushion or padding should be placed over the leg board (unless leg is casted) • Side support may be needed to keep leg from slipping off. 
No footrest 	• Seat is mounted low so that feet rest flat on floor.	• useful for persons who can pull their chair along with their legs and feet–especially when one or both arms or hands are too weak to push the wheels.	• Feet may drag when someone else pushes the child in the chair Swing-away footrests may be the best solution.

FEATURE	DESIGN DETAILS	ADVANTAGES	DISADVANTAGES
PARKING BRAKES **Lever brakes** Brake for wooden chair 	There are many brake designs. This one is from AHRTAG. Two others are on p. 751. SIDE VIEW 	• takes little space • fairly easy to use if made right (which often they are not)	• needs welding and skill to make • Homemade brakes often give problems– yet it is important that chairs have them if possible.
Parking block 	Brakes on wheelchairs are for keeping the chair from rolling when getting in or out, or stopped on a hill. The simplest form of brake is a parking block that keeps the wheel from turning. 	• easy to make requires no welding, and is cheap • If the child usually only gets in and out of the chair in one or two places in the home, blocks in these places may be all that is needed.	• a heavy, awkward object to move from place to place • not practical outside the house (or in it) • have to tilt child to one side to 'park' chair
HANDRIMS FOR PUSHING  	Designs taken from ARHTAG. See p. 730.	• Handrims help keep hands clean. (Otherwise child has to push on tire.) • especially important where there are very dirty paths and roads 	• Added width makes it harder to get through narrow doorways • adds weight
Handrim grip improvers  		• For child with weak or paralyzed hands a smooth rim can be hard to grip– especially if it is chromed or galvanized. • Putting rough cloth tape, a rubber hose or many small handles on the rim will make pushing easier. • Or you can wrap the rim with a long thin strip of car tire inner tube.	• Pegs sticking out from rim increase width of chair. • Pegs sometimes cause hand injuries especially when going fast downhill. 

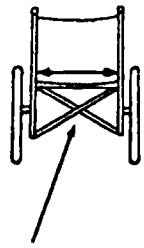
Fitting the chair to the child: measurements

These measurements are for **wheelchairs** and for **special seating without wheels**

SEAT WIDTH



Measure across hips or thighs– whichever is wider.

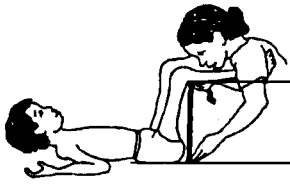


Add 1 cm. (1/2 inch) to both sides for seat width.

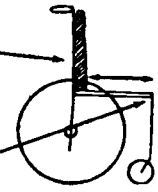
Note: Some specialists recommend wider seats. But the child gets a better arm position for pushing the wheels if only 1 cm. is added on either side, However, you may want to leave a little more room to allow for the child's growth.

SEAT DEPTH

Note: You may want to add 2 cm. or 3 cm. to allow for growth–and use a backboard or firm cushion to till in the extra space.



Subtract about 1 cm. for depth of seat to leave a little space behind the knees.

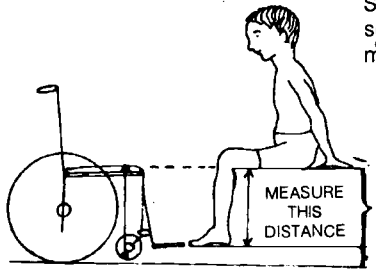


CAUTION: When measuring, be sure to allow for cushions or backboards that will be added.

SEAT HEIGHT

CAUTION: Be sure to include cushion when measuring height for chair seat.

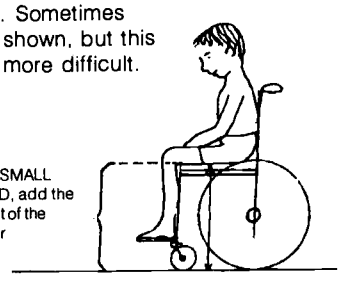
Note: Raising the seat of a small child higher lets his feet rest above the casters and therefore directly below the knees. The higher seat also helps for eating at the table with the family Sideways transfers are also easier. Sometimes seats are placed even higher than shown, but this makes pushing wheels with hands more difficult.



subtract 1 cm. 5 cm.

For and ADULT or BIG CHILD, add 5 cm. for height above ground.

For a SMALL CHILD, add the height of the caster



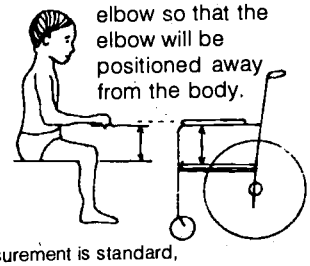
height of caster

ARMREST HEIGHT

MEASURE FROM BOTTOM OF BUTT TO BEND OF ELBOW.

Before measuring, be sure child is sitting as straight as possible.

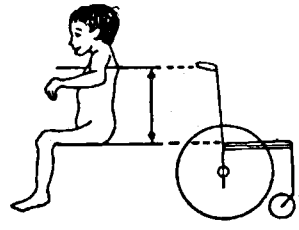
Put armrest height a little higher than his elbow so that the elbow will be positioned away from the body.



Note: This measurement is standard, but some children need arm support at a higher level. Experiment.

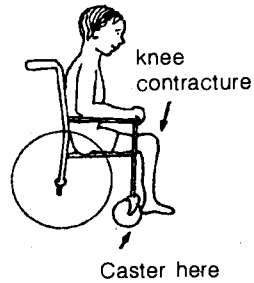
BACK HEIGHT

MEASURE FROM BOTTOM OF BUTT TO ARMPIT.



Note: This measurement is standard, but some children need a higher back, and sometimes head support. Others prefer a back that supports only the hips

IMPORTANT: Also check how much hips and knees bend, as this may affect position of footrests and casters



Caster here will not work.

Wheelchair production as a small 'village–industry'

In several countries small groups of disabled persons have started to produce low–cost, good quality wheelchairs adapted to local needs. Usually this is in places where standard factory–made wheelchairs are very high–priced and are not suited for use on rough or sandy ground.



A disabled worker from PROJIMO paints a wheelchair frame.

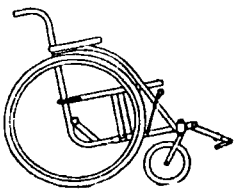
Some of these 'little factories' try to be self–sufficient. A few have even succeeded in making a modest profit, while keeping prices low.

Sometimes, a small–scale wheelchair making and repair shop is set up as part of a community rehabilitation program. Self–sufficiency (selling the chairs for a little more than it costs to make them) is often a goal. But because families with the greatest need are often least able to pay, the chairs must often be sold below cost.

WHAT KIND OF WHEELCHAIRS TO MAKE

This depends on many factors: cost, skills or training available, the possible market, the local economy, and needs of the wheelchair user and family.

For example, folding tube–metal chairs are relatively expensive to make and require more skill, training, and equipment. However, they often work smoother, last longer, and are easier to transport than are many other models. These high–quality, good–looking chairs–painted or even chrome plated with factory–made chairs (see p. 750).



If the wheelchair users will be mostly children and poor families, low–cost wooden chairs may be more appropriate. These can be easily built to size and adapted to the needs of the individual child. The chair may not last as long. But the child is growing and her needs may change. Simple wood chairs also require fewer skills to build–mainly carpentry. They are easier for the family to build, repair, or add changes to at home.

Ideally, a village shop would make a variety of chairs out of different materials and at different prices. Chairs of all models, sizes, and adaptations should be kept on hand to give the child and family a chance to know and try different possibilities. **Be sure to make child–sized chairs. And make chair inserts so that adult–sized chairs can be adapted for children.**

Look for every opportunity to keep costs low. Providing **repair services** for used and broken chairs are good ways to keep children on wheels. Also use as much 'waste', and used and free materials as you can: old bicycle wheels, old machinery bearings, scrap metal, and bolts from junk yards. For basic building materials, check prices of different sellers. Once you are sure of what you need, try to buy large amounts at lower cost. If you explain to the sellers the purpose of your purchase, they may lower prices or give you useful scraps.

Designs for 6 different wheelchairs are in Chapter 67.

How-to-do-it Reference Materials for Wheelchairs. Wheelboards, and Other Seating

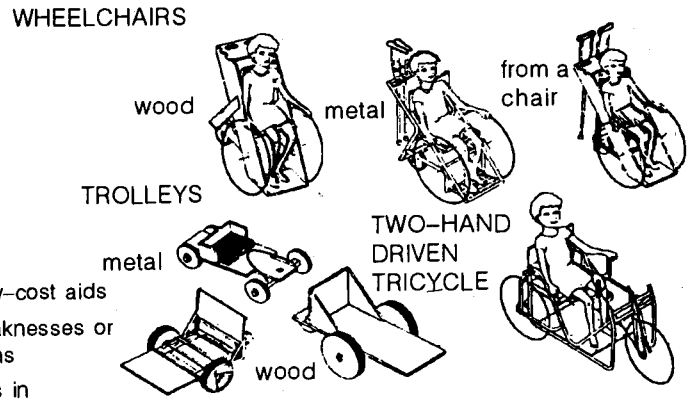
It is impossible, in a book such as this, to give detailed building plans for more than a few wheelchairs, scooters, wheelboards (trolleys), and special seats. The following reference materials have more detailed plans. You can send for them at the addresses shown. Some may also be available from TALC, 30 Guilford Street, London, WC1N 1EH, England, or from the Hesperian Foundation. With each reference we give one or more drawings of key designs and a few comments about their usefulness and cost.

Personal Transport for Disabled People–Design and Manufacture

AHRTAG
Appropriate Health Resources and Technologies Action Group, Ltd.
85 Marylebone High Street
London, WIM 3DE
England

Also available through TALC

- many good designs and plans for low–cost aids
- does not compare strengths and weaknesses or describe limitations of different designs
- no design for wheelchairs with casters in front (which are needed for many areas)

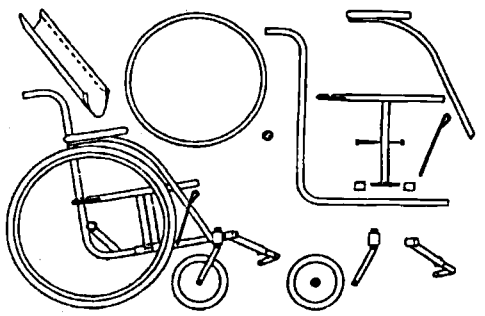


Independence through Mobility: A Guide to the Manufacture of the ATI–Hotchkiss Wheelchair

by Ralf Hotchkiss

Appropriate Technology International
1724 massachusetts Avenue, NW
Washington, D.C. 20036
USA

- design for the 'whirlwind', a high–quality middle–cost steel tube wheelchair that can be built by disabled craftspersons as a village industry
- short training usually needed to build it effectively, welding skills and simple math required
- cost of materials about US $ 100

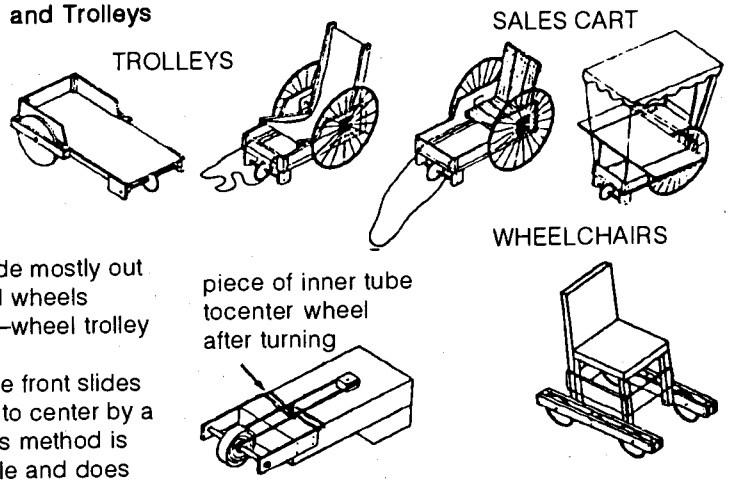


Local Village–made Wheelchairs and Trolleys

by Don Caston
Still unpublished. Available upon request from Don Caston.

5c Edificio Delfin
Av. Joan Miro, No. 279
Cala MayorPalma de Mallorca
Spain

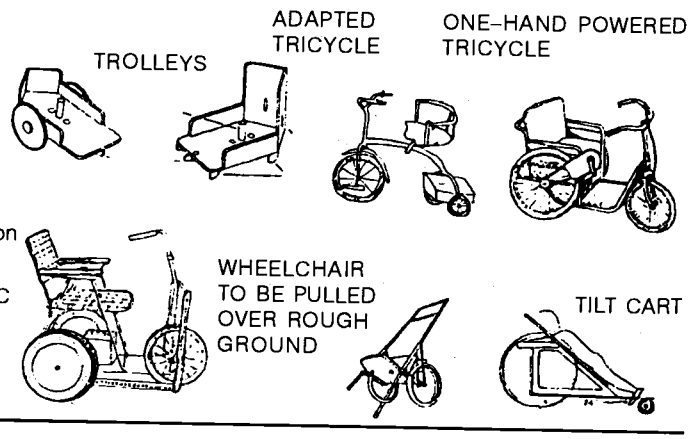
- simple, very low–cost aids, made mostly out of wood, using bicycle or wood wheels
- all models are based on one 3–wheel trolley design
- Instead of a standard caster, the front slides on its axle and is pushed back to center by a choice of simple methods. (This method is cheap and cleaver, but unstable and does not turn as well as designs with casters)



Asia–Pacific Disability Aids and Appliances Handbook, Part1: Mobility Aids, 1982

ACROD/ICTA sub-commission
18 Argyle Street
Sydney, NSW 2000
Australia

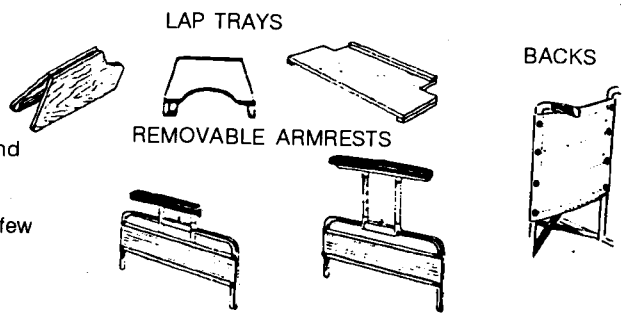
- brief description and non-technical drawings and addresses for information on many aids



An Accent Guide to Wheelchairs and Accessories

Accent Special Publications
Cheever Publishing, Inc.
P.O. Box 700
Bloomington, IL 61701

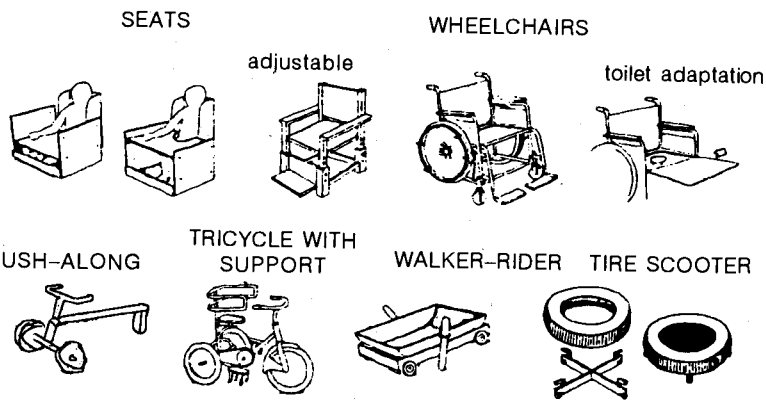
- information about different aids, features, and accessories of factory-made chairs
- basic information on cleaning and repairing
- design and building information limited to a few accessories



UPKARAN–A Manual of Aids for the Multiply Handicapped

The Spastics Society of India
Upper Colaba Road
Near Afghan Church
Bombay 400 005
India

- an excellent resource
- many simple, practical designs for seating, wheelchairs, crawlers, standers, walkers, therapy aids and toys



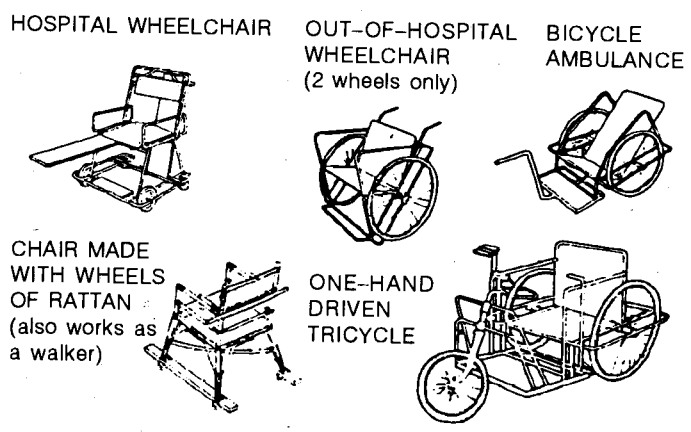
How to Make Basic Hospital Equipment

by Roger England and Will Eaves

Intermediate Technology Publication, Ltd.
9 King Street
London, WS2E 8HN
England

Also available through TALC and AHRTAG

- simple, attractive desings using tube steel
- welding skill required: fairly costly to make
- no designs for casters-in-front chairs



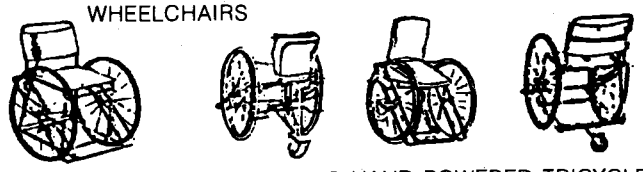
Poliomyelitis– A Guide for Developing Countries

by R.L. Huckstep

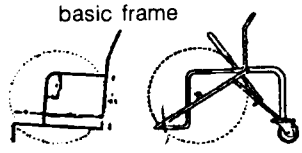
Churchill Livingstone
1–3 Baxter's Place, Leith Walk
Edinburgh Eh1 3AF
Scotland

- detailed designs for 3 models of wheelchairs commonly used in Africa
- only casters–at–rear desings (which often may not be the most appropriate design)

WHEELCHAIRS



basic frame



2–HAND POWERED TRICYCLE



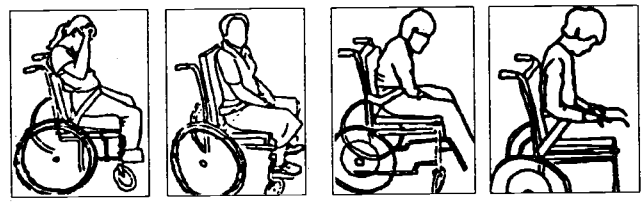
Positioning the Client with Central Nervous System Deficits: The Wheelchair and Other Adapted Equipment

By Adrienne Falk Bergen and Cheryl Colangelo
Valhalla Rehabilitation Publications, Ltd.
P.O. Box 195
Valhalla, NY 10595
USA

- excellent detailed discussion of specific needs of children with cerebral palsy
- many well–illustrated examples
- written for developed countries but many aids and designs are simple and can be made anywhere at low cost

SEAT BELTS

WRONG RIGHT RIGHT WRONG



This child, whose hips tilt forward, needs a higher belt.

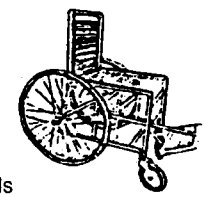
This child, whose hips tilt back, needs a low belt.

'Build Yourself' Plastic Wheelchair

Directions for assembly available from:

Spinal Research Unit
Royal North Shore Hospital of Sydney
St. Leonards, NSW 2065
Australia

- relatively expensive (materials about US $ 100)



- Plastic frame made of 9 m. of 15 mm. PVC pressure pipe: plastic set of 8 mm. soft PVC tubing; 2 rear 24 inch bicycle wheels; 2 front casters (15 mm.)
- relatively expensive (materials about US $ 100)
- Plastic will sag with continued use.
- uses standard bicycle axles–which will bend with the weight of an adult or large child
- relatively lightweight
- does not fold
- design plan complicated and difficult to follow

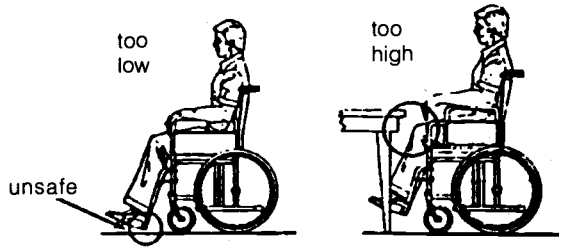
Measuring the Patient

Everest and Jennings, Inc.
Available through Everest and Jennings wheelchair
dealers or:

Everest and Jennings
3233 East Mission Oaks Blvd.
Camarillo, CA 93010
USA

- good information on measurements for standard chairs
- illustrated discussion of problems with chairs that do not meet a person's

SEAT HEIGHT



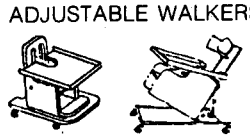
Functional Aids for the **Multiply Handicapped**

by Isabel Robinault

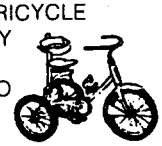
Harper and Row, Publishers
Hagesrstown, Md
USA

- mostly factory–built examples but some are simple and well–illustrated enough to serve as design guides
- many good wood special seats
- also support frames, standers, walkers, toys, and eating aids

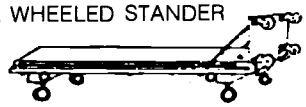
SMALL–WHEELED ADJUSTABLE WALKERS



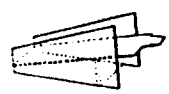
CHILD'S TRICYCLE WITH BODY SUPPORT BOLTED TO FRAME



SCOOTER THAT IS ALSO A WHEELED STANDER



SUPPORT FRAME



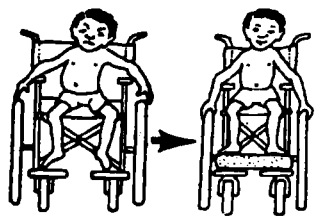
CHAPTER 66

Adaptions for Wheelchairs and Other Sitting Aids

Many children need more support or special ***positioning*** than is usually provided by a regular chair or ordinary wheelchair. So we should try to **get or make a chair designed to fit the individual child.** Unfortunately, many children get wheelchairs that are much **too big.** Often no others are available. Here are 3 ways to adapt them. (CP)

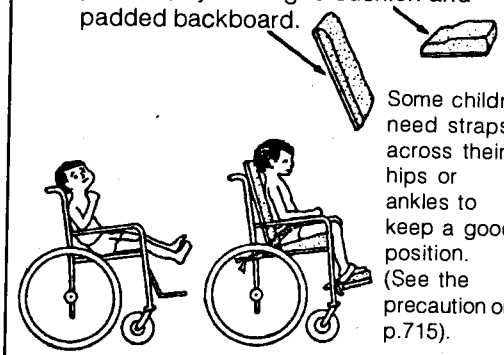
1. **If a folding chair is too wide** make the cloth seat and back narrower. The chair will not open as wide (but may be too high).

TOO WIDE NARROWER (BUT HIGHER)



Be sure to check how well the child can reach to turn the wheels.

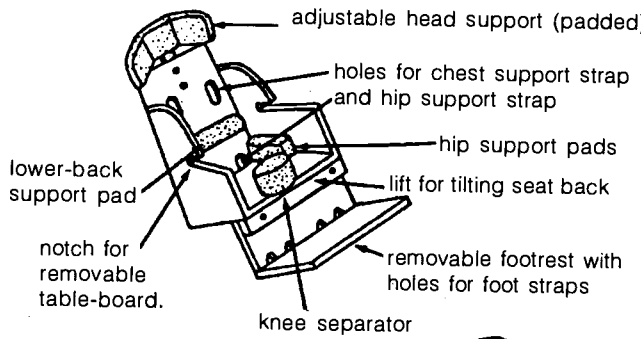
2. **If the chair is too big from front to back,or** if the child needs a better position, try a wedged cushion and padded backboard.

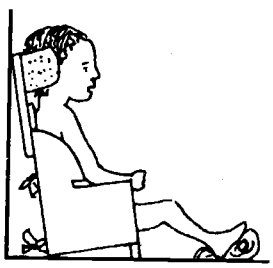


Some children need straps across their hips or ankles to keep a good position. (See the precaution on p.715).

3. **If still more help is needed** for positioning the child, make a **sitting frame** designed to meet her needs. Here is an example.

CAUTION: Not all children will need all the special features shown here. Some will need still other features. Adapt special features to the needs of the particular child, and **test them before making them permanent**

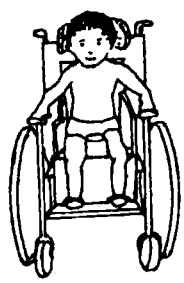




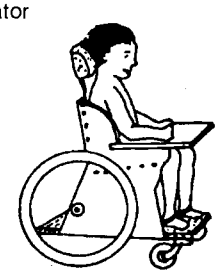
The sitting frame can be used on the ground.



It can be placed in a chair(or strapped into the seat of a car).



It can be fitted into a wheelchair.



Or make a simple wood wheelchair with all the features of the sitting frame (see p.748 and 749).

(CP)

Seating adaptations for specific children

The various adaptations discussed here are designed to meet specific needs of individual children, especially children with cerebral palsy. Remember that **each child's needs are different,** and adaptations that are not carefully fitted to the needs of the child may do more harm than good.

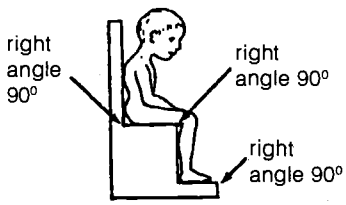
1. **Carefully consider the child's specific needs before** including any adaptation or special seating.
2. After making an adaptation,**evaluate how the child uses it.**
3. **Check often** to see if it continues to help the child. An adaptation for a growing child may help her progress at one stage of development but hold her back a few weeks or months later.

General position

We have talked about this a lot, but it is worth repeating:

USUALLY RIGHT

Most children who require special seating sit best with their hips, knees, and ankles at right angles.



USUALLY WRONG



A chair shaped like this may cause a child with *spasticity* to stiffen and straighten,or cause a severely *paralyzed* child to slip forward and slump.

ANGLE OF BODY AND HEAD

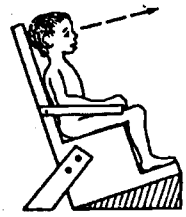
A slight backward tilt helps most children sit in a better,more relaxed position.



If the child still falls or stiffens forward

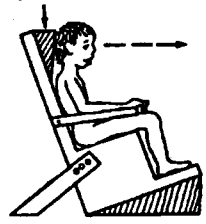


it may help to tip the chair back even more.

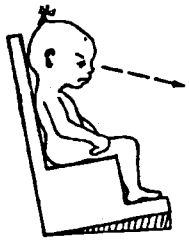


However, this may cause his head to lean back so his eyes look upward.

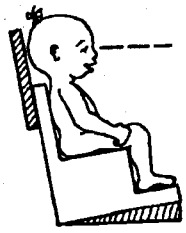
A head pad may help position him to look forward, and may decrease some spasticity. It can also reduce spasticity in the eye muscles.

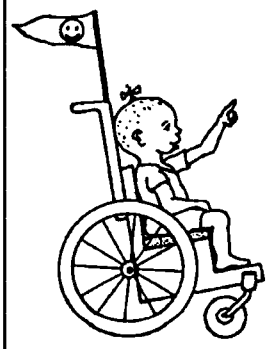


The heads of babies and small children may be so big that the headrest tilts them forward so their eyes look down.



Putting the headrest behind the level of the backboard lets the child hold her head in a better position.





REMEMBER: All the seating ideas shown on these pages apply to wheelchairs, and also to special seats without wheels.

CP

Other ways to help keep hips at a right angle

HIP STRAPS

If the hips tilt back like this,



a high hip strap will not help much.

WRONG



A low hip strap helps keep the hips at a good angle.

RIGHT

But if the hips tilt forward like this.



a low hip strap will not help much.



A high hips strap helps keep the hips at a better angle.

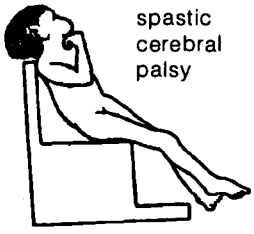
Notice that in both of these children with cerebral palsy, supporting the hips in a better position helps the whole body take a more normal position.

SPECIAL CUSHIONS

For the child whose hips tilt back, or whose upper body is 'floppy', **a padded support across the lower part of the back** may help her keep a good position.

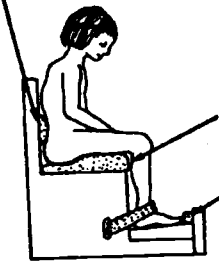
Good cushions sometimes make straps unnecessary.

WITHOUT CUSHIONS

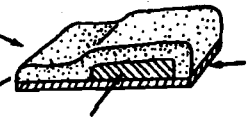


child with spastic cerebral palsy

WITH CUSHIONS



sponge rubber padding

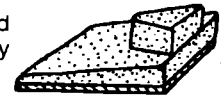


thin wood base

block to keep hips from slipping forward

This cushion helps keep the hips from coming forward.

Pad toe rest to prevent cuts and sores caused by spastic push.

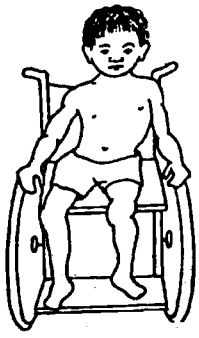


A padded post may also help to keep hips back and legs apart (see next page)

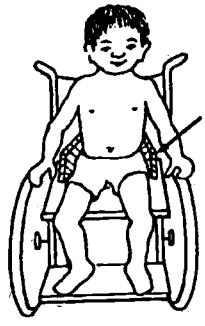
A footstrap or block that keeps knees bent may help keep the child from straightening stiffly.

Note: Cushion designs for spinal cord injury are on p.234.

Keeping the body straight from side to side

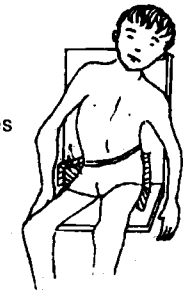


Even with a firm board seat, this boy's body sags to one side. This can lead to increasing curve of the spine (scoliosis).

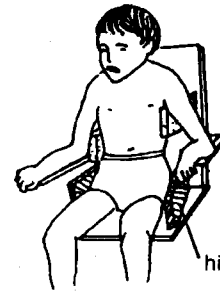


hip guides

Hip guides may help him sit straighter



Sometimes, hip guides alone are not enough.



Padded body guide

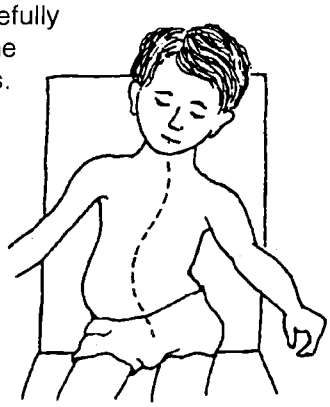
hip guide

He may also need carefully placed body guides, to help keep his body in a straighter position.

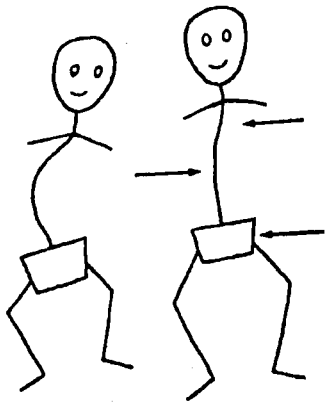
Deciding where to place body guides

CP

1. Look carefully at how the child sits.



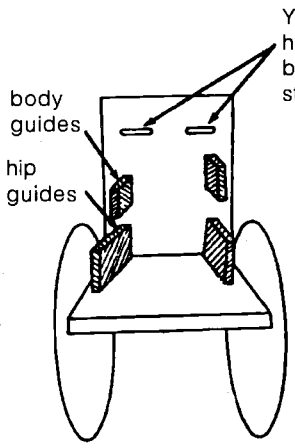
2. Draw a sketch of how he sits. Then draw arrows where you would need to push to help him sit straighter.

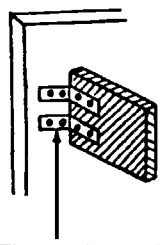


3. While someone holds the child in his best position, mark where you think the guides should be placed.



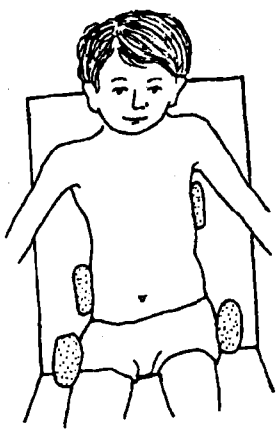
4. First, build in the guides in a temporary way.



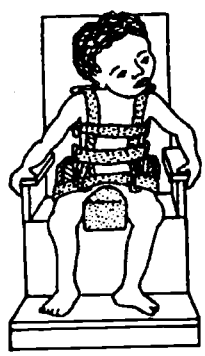


The guides under the child's arms should be thin. To hold their position you can use angle irons.

5. See how well the child sits in the adapted seat. When you cannot improve it more, fasten the guides firmly and pad them so they do not hurt him.



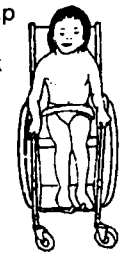
An 'H' harness, with straps that pass through slots in the backboard, is another way to help hold steady the body of a severely disabled child.



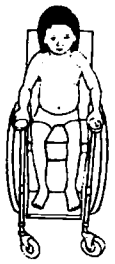
Carefully evaluate what kinds of support each child needs.

Maria's legs straighten, press together, and turn inward. Her whole body position is affected.

A **hip strap** holds her hips back some but does not help her overall position much.

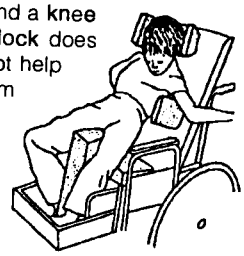


However, a **backboard** that bends her hips more, plus a **knees post,** help improve her whole body position **without straps!**

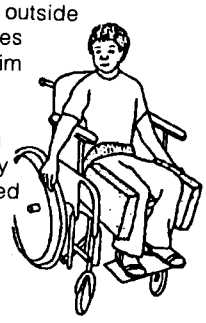


Pedro is a heavy child whose body stiffens and his knees push open.

A combination of a **backboard** with guides, a special **cushion** and a **knee block** does not help him



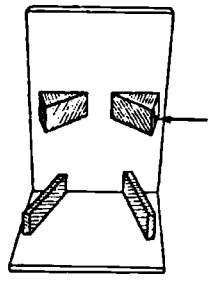
However, a **hip strap** together with **blocks** outside his knees gives him a much better position (He may also need foot straps).



SHOULDER-BLADE WINGS

Pablito's spastic muscles pull his shoulders back and make it hard for him to bring his hands together in front of him. The village team had an idea.





They put 'wings' behind his shoulder blades, like this, to help keep his shoulders forward.

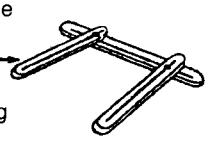


Now Pablito can bring his hands together and play more easily.

LAP BOARDS

These can be made from thin wood, plywood, or fiberboard. They should be easy to take off, but grip firmly when in place.

You can make a simple instrument out of cardboard or stiff paper to measure the child's body for cutting out the lap board.



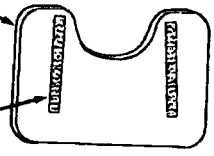


Extra holes for changing peg position.

Raised edges help keep toys from falling.

Two pegs to hold onto may help him sit, or move into a better position. They also help him develop hand control. (games with rings, etc.,)

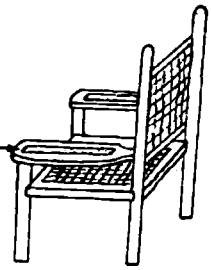
A **lap board** can help keep shoulders, arms, and body in a better position, especially if it has a part cut out measured to fit around the child.

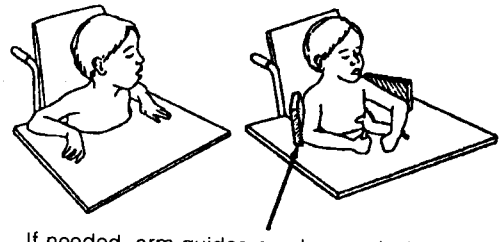


"Velcro"(stick-to-itself tape) can be used to fix the board to the chair for easy removal and to adjust it forward or backward.

Height of the lapboard is usually the same as for armrests (see page 728). Experiment to find out what works best.

Be sure to put the softer part of the *Velcro* on the chair arms. The rough parts could scratch the child when the board is not used

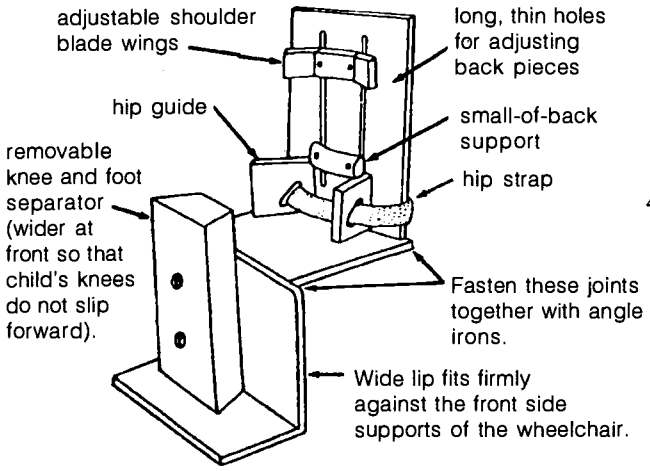


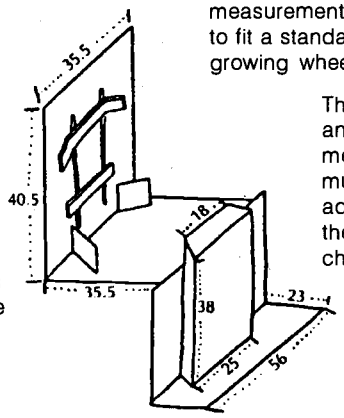


If needed, arm guides can be used with a lap board to keep a child's shoulders forward and his arms in a better position to use his hands.

DESIGN FOR A WHEELCHAIR INSERT

This insert, from ***Positioning the Client with Central Nervous System Deficits*** provides a lot of control, and is especially useful for some children with spasticity. Although it was designed as an insert for a wheelchair, you can use it as the frame of a wooden wheelchair, or chair without wheels built for a specific child.



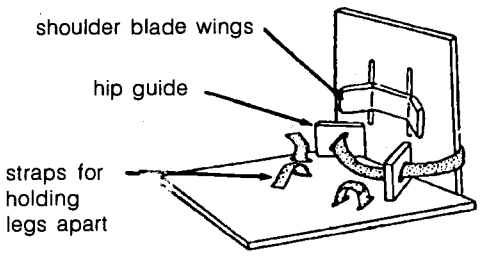


measurements of an insert to fit a standard 'junior growing wheelchair'

The height and depth measurements must be adapted to the individual child.

Measurements are given in centimeters (cm.). To change inches, divide by 2.5.

DESIGN FOR A STRAIGHT-LEG SITTING FRAME
(mostly for very young children)

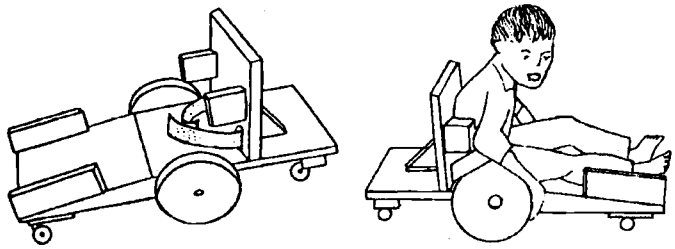


To seat the child, the frame can be pout on the ground, a table, a chair, or into a wheelchair.



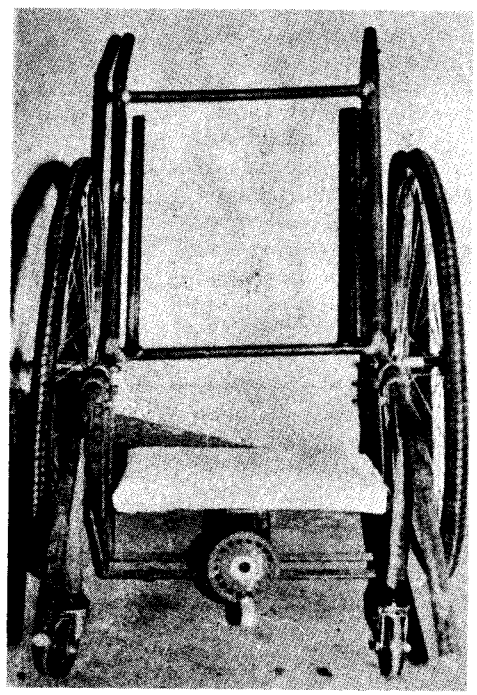
DESIGN FOR AN ADAPTED CASTER CARD WHEEL BOARD

Use the same suggestions for supports, guides, and straps.



Note: The child's weight is over the large wheels. He can rock from one caster to the other. For travel over rough ground, he will learn to balance on the center wheel and barely touch down with the others.

CAUTION: Be sure to add cushions or adequate padding to all seating designs. Children whose bodies push in uncontrolled ways can very easily develop pressure sores. (see Chapter 24)



Example of a locally made Wheelchair
SELF-HELP Wheelchair

CHAPTER 67

Design for 6 Basic Wheelchairs

There are dozens of designs for low-cost, 'appropriate technology' wheelchairs. Some are lower cost and more generally useful than others. In PROJIMO, we have built many different wheelchairs. In this chapter we give designs for 6 of the ones that we have found most useful. Each has advantages and disadvantages.

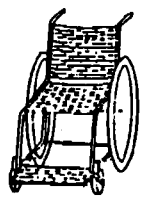
AHRTAG wood wheelchair made from a child's chair, bicycle wheels and axles at front, one rear caster



Advantages: the simplest and one of the cheapest chairs to make; easy to modify or adapt; very little welding needed: can be built in one day by someone with some carpentry skill; low cost.

Disadvantages: Single, small rear wheel makes it difficult for either the child or helper to push over rough ground or up curbs. Fixed footrest makes it hard for child to climb in and out without tipping chair forward when weight is on footrest. Sideboard makes ***transfers*** to side and lifting child from behind difficult.

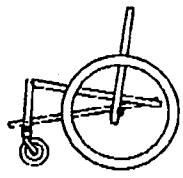
Re-bar and woven plastic wheelchair steel construction rod frame with woven plastic seat, back, and footrest



Advantages: simple design; fairly low-cost re-bar easy to bend; plastic woven seat is comfortable and easy to clean; slide-away footrest makes getting in an out easier.

Disadvantages: Builder needs welding skills; relatively heavy and not as strong as tubing chairs. Big bumps may bend the chair out of shape.

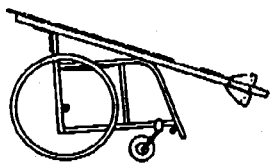
Square metal tube wheelchair frame bolted together



Advantages: strong, stable metal chair that can be built with nuts and bolts (welding needed only to attach front wheels). Flat surfaces make it easier to put on wood ***adaptations;*** fairly low cost.

Disadvantages: more work and skill needed than for above chairs; design more complex; slightly higher cost than wood chairs.

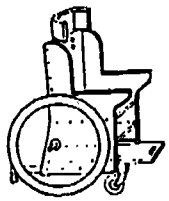
Wheelchair with lying board made of steel tubing, with removable wood lying board



Advantages: useful for active child who must lie face down to heal sores or stretch ***contractures.*** When board is removed, it is a regular wheelchair; low cost; very adaptable.

Disadvantages: requires welding (but a simpler model can be made of wood); does not fold; board takes up a lot of space; stiff ride.

Plywood frame wheelchair with 20 inch bicycle wheels and axles, and 2 front casters



Advantages: attractive; lightweight; low cost, easy to make and adapt. Caster wheels in front (not in back) make it easier to go over rough ground and curbs. Adjustable push-away footrest makes ***positioning*** and getting in an out easy.

Disadvantages: Plywood and double casters increase cost (although it is still a cheap chair). Plywood (if not marine grade) may come apart in wet weather. Bicycle axles may bend or break with a heavy child or rough use.

Metal tube folding wheelchair made from thin-wall steel tubing; strong axles with machinery bearings



Advantages: Chair folds for transporting or storage; very tough; flexible design good for uneven surfaces; good for side transfers; a very high-quality chair if well-made.

Disadvantages: needs more skill (tube bending, welding, exact fittings, wheel spoking, etc.) to build; relatively costly; hard to adapt.

Tools needed for making wheelchairs

Ideas for setting up a workshop for ***disabled*** workers are discussed in Chapter 58 and p.729 of Chapter 65. How you equip your workshop for making wheelchairs will depend on (1) how much money you have (or can borrow) to do it, (2) the kinds of chairs you hope to build (metal or wood), (3) the skills, ***physical*** and ***mental*** abilities, learning potentials and responsibility (regarding safety) of the workers, (4) the availability of electricity and power tools, (5) how many persons will be working, and (6) how many chairs you hope to produce.

Here we list the basic equipment you will need for making the 6 wheelchairs described in this chapter. Many choices are possible. More specialized parts of the work can be done by outside craftpersons. For example, in a wheelchair production center in Belize, axles must be machine tooled on a metal lathe. Local machine shops cooperate by doing this free.

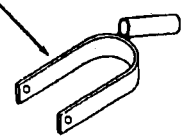
CODE AN – Absolutely necessary N – A big help, but you might do without it (N) – Necessary only for axles ? – Depends on model	TYPE OF CHAIR					
	wood chair	re-bar and woven plastic	square metal tubes with wood seat and back	wheelchair with lying board	plywood	round metal board
TOOLS REQUIRED						
bench wise	N	AN	N	AN	(N)	AN
tubing bender				AN		AN
welding (brazing) equipment	(N)	AN	N	AN	(N)	AN
metal saw	(N)	AN	AN	AN	(N)	AN
wood saw	AN			AN	AN	
hammer	AN	AN	AN	AN	AN	AN
wrench (set or adjustable)	N	N	AN	AN	N	AN
metal file/or grinder	(N)	AN	AN	AN	(N)	AN
screwdriver	AN	AN	AN	AN	AN	AN
sewing equipment (hand or machine)			?	N?		N?
drill (hand or electric)	N	?	AN	AN	N	AN
drill bits for metal			AN	AN		AN
drill bits for wood	AN		AN		AN	
spoke wrench	?	?	N	N	?	N
bicycle pump	?	?	?	?	?	?
centre punch	N	N	N	N	N	N
tape measure	N	N	N	N	N	N
carpenter's square	N	N	N	N	N	N

Terms for metal tube or bar used to build wheelchairs

- *Thin-wall* refers to thin steel tubing often used for electrical wiring work and sometimes for lightweight metal furniture.
- *Thick-wall* refers to heavy weight pipe such as the one used in plumbing.
- *Re-bar* refers to solid metal rod, usually used to reinforce cement.

Jigs or guides for more exact welding

For making the metal tube chairs and the welded wheel mounts and handrims of any of the chairs, your work will be easier and more exact if you make or purchase certain 'jigs' or guides to hold parts in the right place while you weld them. For example, to weld the front caster fork you can make a 'jig' like this.



Details on 'jigs' and other techniques for making different wheelchair parts are well described in Ralf Hotchkiss's book *Independence Through Mobility* (see reference on p.730). We strongly recommend it to any group planning to make wheelchairs.

Notes on measurements

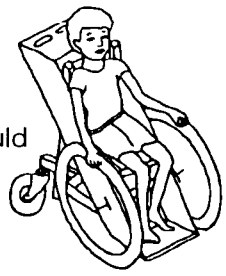
For some of the wheelchair designs in this chapter, we give the measurements for a standard child's or adult's model. **Be sure to adapt the measurements to the size and needs of the particular child.**

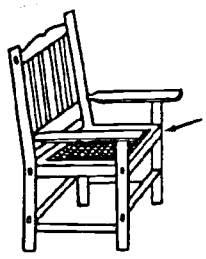
In many countries inches (") are used for measurements of certain things, and centimeters (cm.) for others. We therefore also use both. **Centimeters** is abbreviated **cm.** and **inches** is abbreviated." Two inches is written **2". 1" equals 2.54cm. You can use the scale on the edge of this page (and on the inside back cover) to change inches to cm.**

AHRTAG WOOD WHEELCHAIR

(Somewhat modified from AHRTAG manual, see p. 730.)

The AHRTAG wheelchair is built onto an ordinary **child's wood chair.** Measurements should be adjusted to the child's needs.





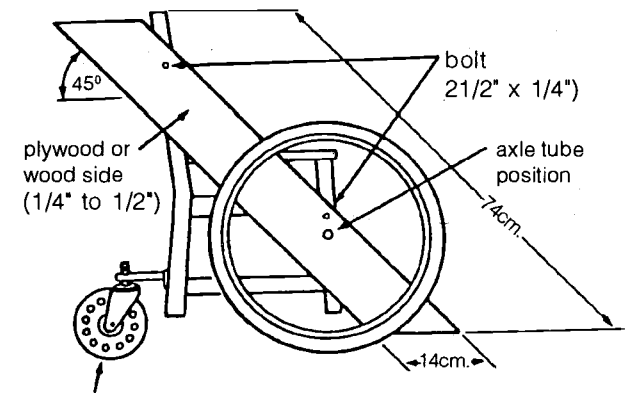
A webbed plastic seat lets air move through it an can be easily cleaned.

It uses standard 20" x 1 3/4" bicycle wheels and axles.

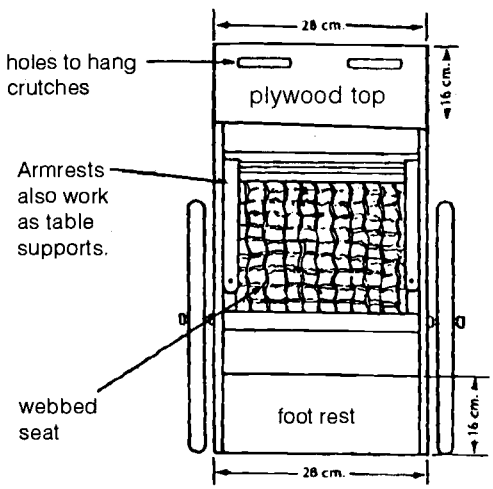


Basic carpentry tools are needed to build this wheelchair. It can be made in one day by someone with basic carpentry skills. The local blacksmith may be able to help weld together the wheels supports if you cannot. It is easy to add positioning aids or make other adaptations. The cost in Mexico using new materials is about US$40.00.

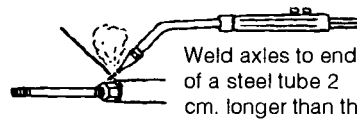
SIDE VIEW



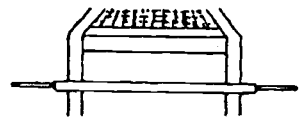
TOP VIEW

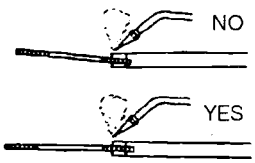


AXLES



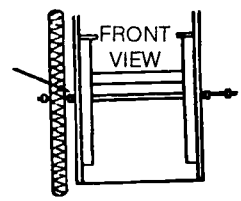
Weld axles to ends of a steel tube 2 cm. longer than the chair is wide.





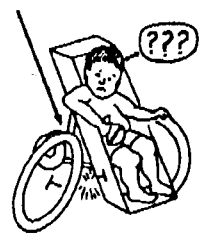
Weld axle perfectly straight.

Pass axle tube through holes drilled through sideboards and front chair legs.

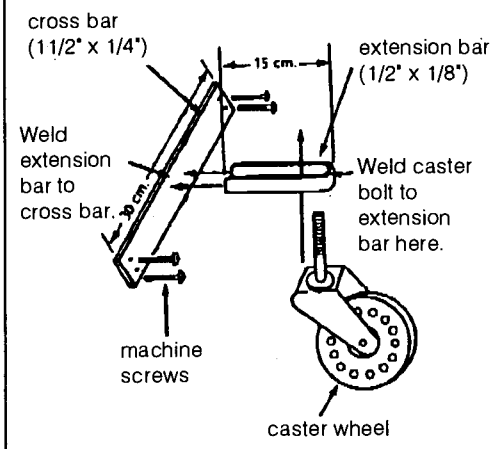


WARNING: Use standard bicycle axles this way only for children under 20 kg (50 lbs.). A heavier child, or rough use, will bend or break the axle.

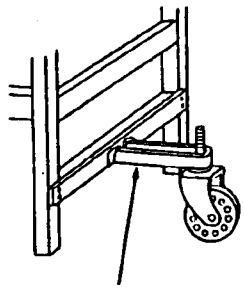
For children over 20 kg., use a stronger axle (see p.751). Or support the bicycle axle from both sides (see p. 724).



CASTER

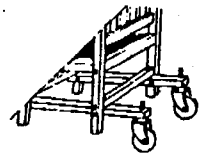


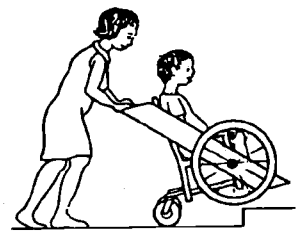
BACK VIEW



This backward extension distributes weight better and keeps chair from tipping backward on hills.

Two back casters are more stable and make it easier for the wheelchair to go up curbs.

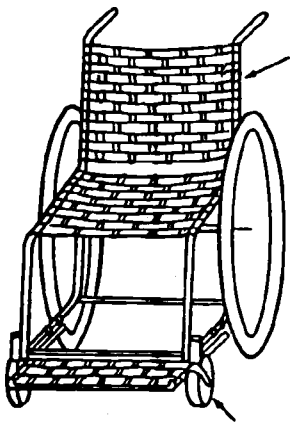




For brake designs, see p.727 and 751. For other pictures and models of the AHRTAG wheelchair, see p.638, 718,726,727,730 and 752.

RE-BAR AND WOVEN PLASTIC WHEELCHAIR

Total cost using new parts is about US $40.00.

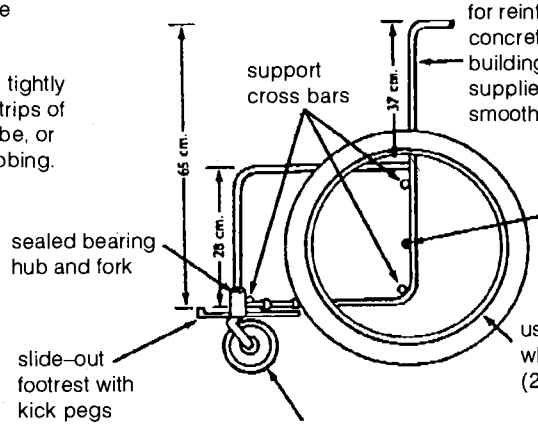


Weave back seat, and footrest with ribbon, local wicker, cane, rattan or polyethylene plastics.

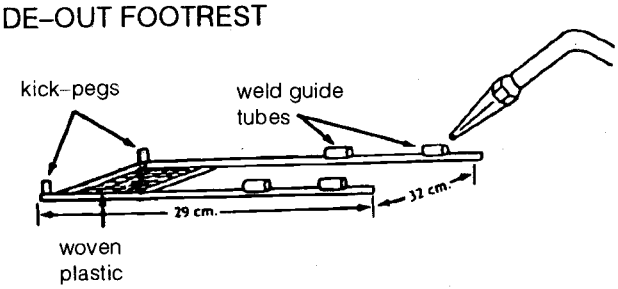
Or use thin, tightly stretched strips of car inner tube, or canvas webbing.

For **front fork and casters,** use factory made casters or make your own (see above, and p. 723, 747, and 751).

SIDE VIEW



SLIDE-OUT FOOTREST



MATERIALS NEEDED

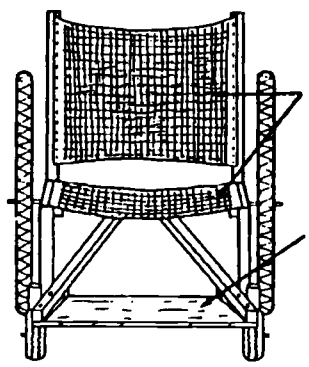
- 1/2" re-bar (4 1/2 meters)
- inner tube strips
- bicycle wheels (2)
- front casters (2)
- webbing for seat

For **axle designs** see p. 723, 724, 743, and 751.

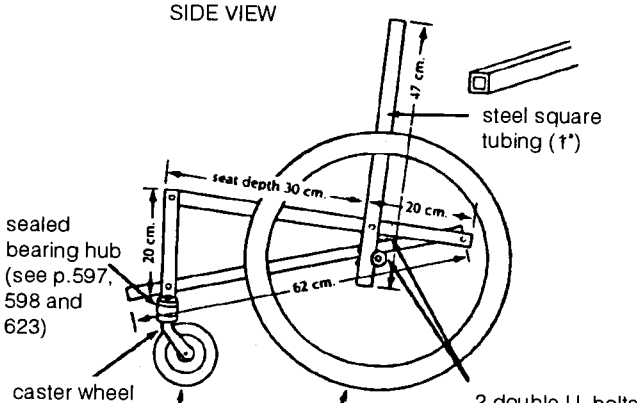
SQUARE TUBE WHEELCHAIR

This wheelchair, like other steel tube chairs, should use only thin–wall tubing. Total cost in Mexico using new parts is about US$40.00. To keep costs down, check with various sources of materials and ask at small fix–it shops for advice and possibly even some free scrap material. Metal scrap heaps are great for materials.

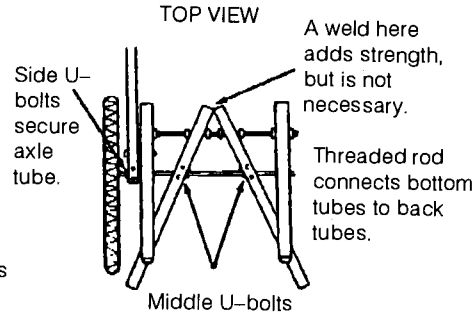
FRONT VIEW



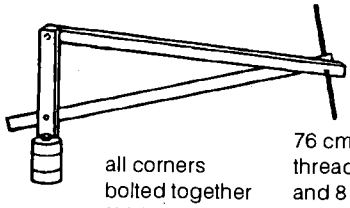
SIDE VIEW



TOP VIEW



SIDE VIEW

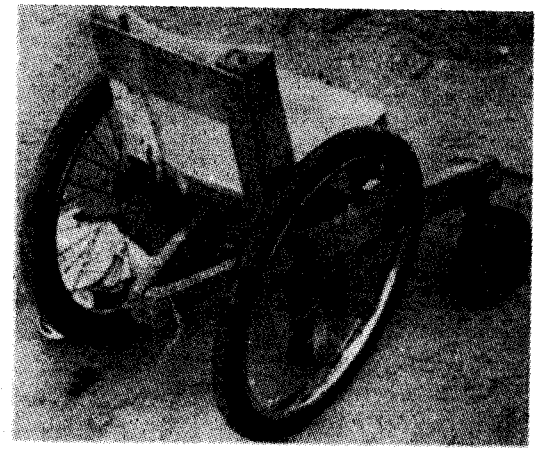


MATERIALS NEEDED

- thin–wall square tubing (1" x 3.64 meters)
- thick canvas cloth (1 square meter)
- galvanized steel tube (1/2" x 66 cm.)
- bicycle wheels (2) (20" x 1.75")
- caster wheels (2) (wood or rubber)
- threaded rod (3/8" x 38") (Use extra 20" to bend 4 U–bolts.)
- 2 front casters
- 21 3/8" nuts and 12 screws for seat and back supports

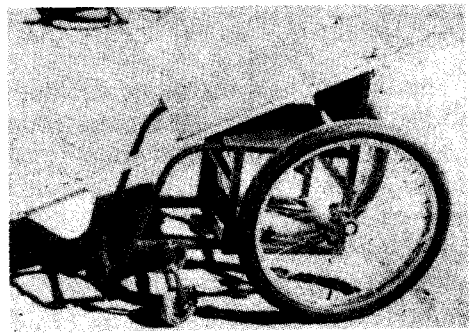
HOW TO MAKE YOUR CHAIR

1. Review drawings. Adjust measurements to fit child.
2. Cut all sections of square tubing. Make sure that matching tubes are equal in length.
3. Drill holes in bottom tubes and pass the threaded rod through them. Adjust nuts until a 'V' is formed. (Weld tip of 'V' for extra strength.)
4. Drill all holes in seat tubes. Pass threaded bolt through seat holes.
5. Drill holes in back support tubes and front caster tubes. Bolt to frame.
6. Weld axle nuts to ends of axle tube. Drill holes for U–bolts and bolt axle tube to frame.
7. Weld front caster forks to front tubes.
8. Sew cloth back seat supports. Screw into place.
9. Cut out and bolt wood footrest to frame. (Use wedges to get the angle right.)
10. Attach axle tube with U–bolts and put on the wheels.
11. Paint frame to help keep tubes from rusting (if not galvanized).



The same design can be made of wood.

WHEELCHAIR WITH LYING BOARD



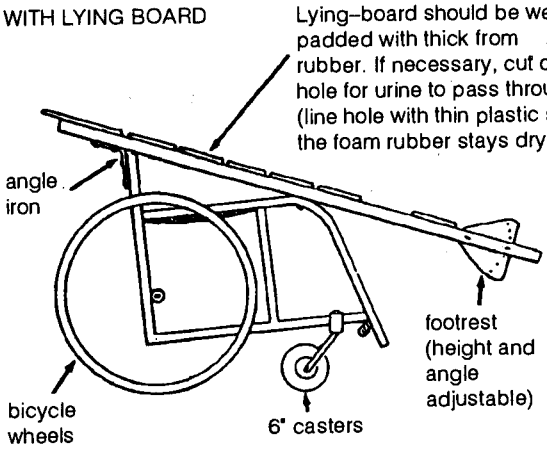
This is useful for an active child who must lie face down to heal pressure sores or to stretch hip and knee contractures.

The board is sloped so that the child can play, look ahead, and move about more easily. If necessary, you can make the lying board adjustable so that the child can rest lying flat. This helps to improve ***circulation*** and to prevent swelling of the feet.

After the pressure sores heal, the lying board can be removed and the frame is easily adapted to form a lightweight wheelchair. The cost for materials in Mexico is about US $40.00.

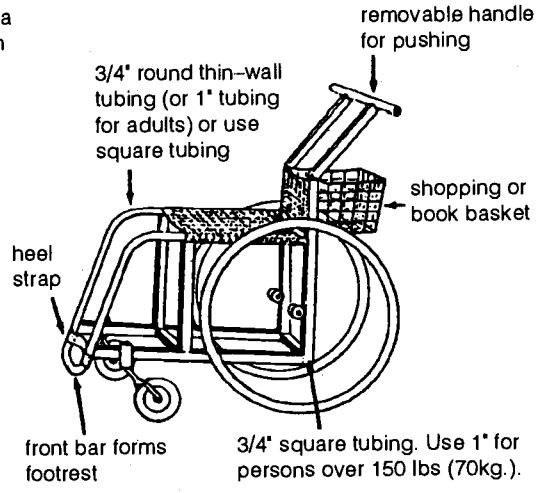
The design we show uses a simple, non-folding steel tube wheelchair frame with a wooden lying board mounted on top. However, many other designs are possible. (See, for example, the photo of a lying and standing wood wheelchair on p. 223.)

WITH LYING BOARD



For tall persons, place the casters farther from the big wheels to help prevent tipping.

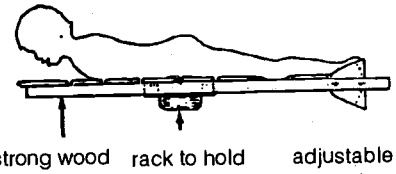
WITHOUT LYING BOARD and with other additions



THE LYING BOARD

SIDE VIEW

Attach thin wood or plywood boards with small screws so that they can be easily adjusted to leave open spaces under bony parts or sores.

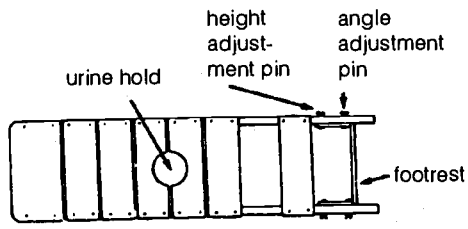


strong wood pole (or 1" square tubing)

rack to hold urine pot (if needed)

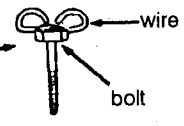
adjustable footrest

TOP VIEW



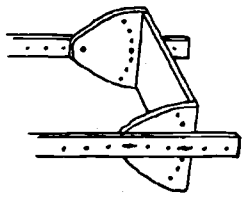
Make the board and wheelchair just a little wider than the child's hips.

The board attaches to the chair with angle irons or **wing bolts**. You can make wing bolts by brazing a stiff bent wire to a bolt.

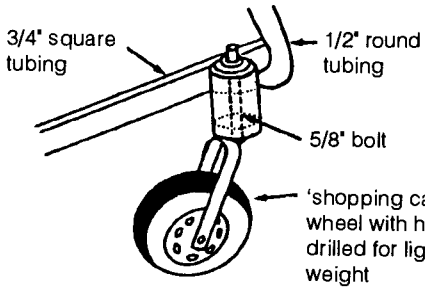


FOOT REST

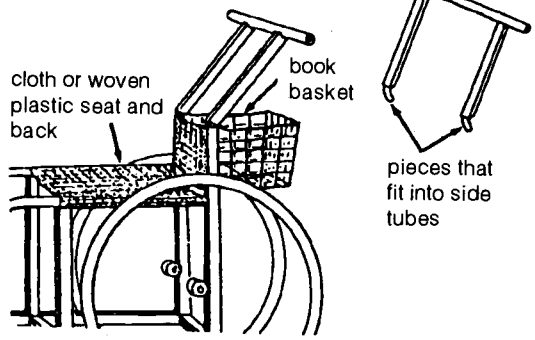
Use thin wood or plywood. (Pad sides and bottom well to prevent sores. Examine feet daily.)



FRONT CASTER WHEEL



REMOVABLE HANDLE



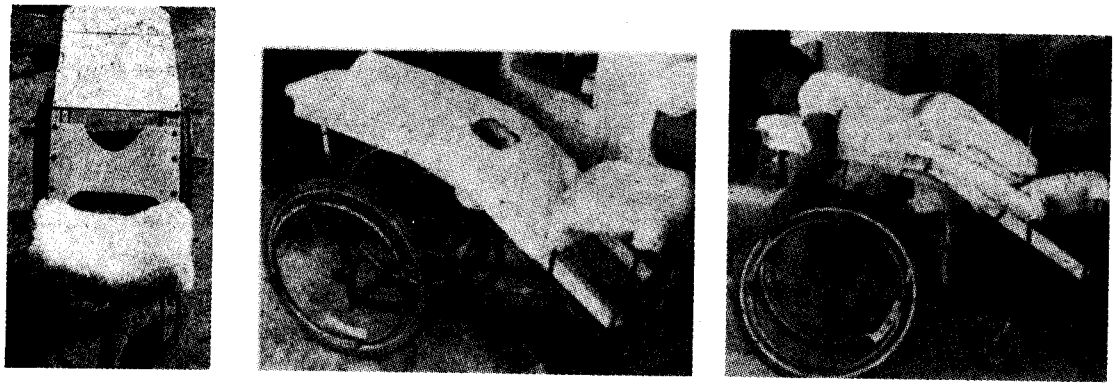
You should now have enough information to make a wheelchair with a lying board without step-by-step instructions. Adapt it, and make it the size to fit the child that needs it.



Wheelchair with lying board. A wide strap holds the child in place (but take care it does not press on sores).



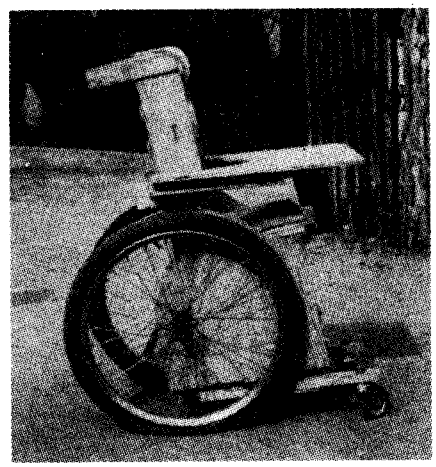
Wheelchair without lying board.



A variation of the wheelchair with lying board (p.746) adapted for a paraplegic child with both contractures and pressure sores of his hips and knees. Urine is collected in a plastic container. The wheelchair seat has been converted into a basket.

CAUTION: Remember that a child who has some pressure sores can easily get new ones. Be sure the child lies and sits so that there is little or no pressure over bony places. **Examine her whole body at least once a day and try to keep her dry.**

PLYWOOD FRAME WHEELCHAIR

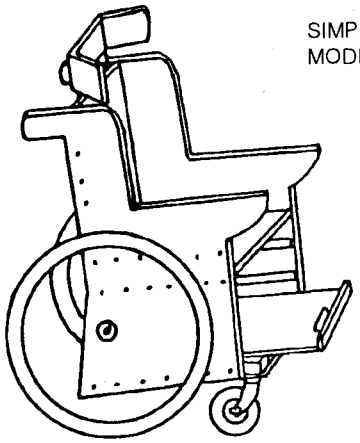


This can be easily built by someone with basic carpentry and welding skills. (Cost in Mexico using new materials is about US$ 40.00.) Positioning aids (head rest, hip pads, etc.) can be easily added. The chair can be designed to meet a child's particular needs. For example, if the child sits well without extra support, the tops of the side pieces can be removed to allow more freedom of movement.

A plywood frame is a low-cost alternative to metal. However, if not made well, or if left out in the rain, the chair may weaken and the plywood can split. As with any wheelchair, it must be protected from misuse, periodically examined for weaknesses, and promptly repaired.

See model on p. 749 →

For active children the wheelchair can be strengthened by reinforcing all joints and by adding strong hubs and axles (see p.751).

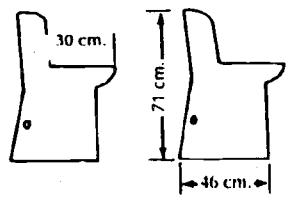


SIMPLE MODEL

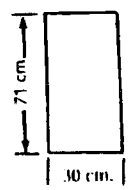
HOW TO MAKE YOUR CHAIR

1. Review drawings of chair and adaptive equipment.
2. Cut out the two side pieces to the same shape; sand with sandpaper.
3. Cut out back support, seat, and bottom piece of chair; sand with sandpaper.
4. Screw or nail seat and bottom piece to back piece.
5. Screw or nail side pieces to seat, bottom, and back.
6. Check that all pieces are lined up straight. Then add glue and more screws or nails for strength.
7. Cut out footrest and guide brackets for footrest.
8. Screw or nail guide brackets to side pieces under seat.
9. Bolt front casters to chair and assemble rear axle tube.
10. Drill holes in side pieces for axle tube; mount tube and rear wheel.
11. Let glue dry 1 or 2 days; check for strength of all wood joints.

These measurements are for a 4 to 8 -year-old child.



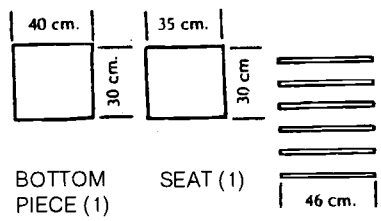
SIDE PIECES (2)



BACK SUPPORT (1)

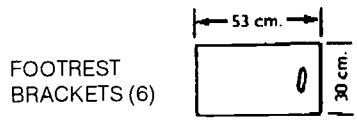
MATERIALS NEEDED

- 3/8" plywood (1 sheet)
- 20" bicycle wheels (2)
- small caster wheels (2)
- 1/2 steel tube (66 cm. long)
- wood glue
- sand paper
- screws
- nails
- 1/2" by 1/4" wood strips (6 x 46 cm. long)



BOTTOM PIECE (1)

SEAT (1)



FOOTREST BRACKETS (6)

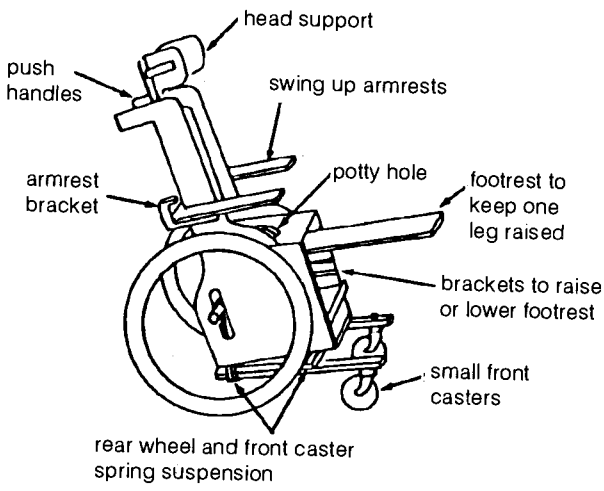
(1/4" to 1/2")

FOOTREST (1)

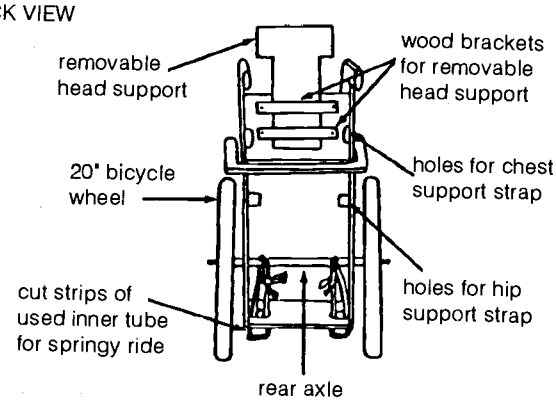
A plywood wheelchair with many adaptations

This wheelchair has a variety of additions sometimes needed for a small child who has poor body control, head control, and urine or bowel control. The head support and arm-rests fit into wooden holders and can be easily removed. A lap table can be easily added. Holes can be cut out for chest and hip straps for extra support.

SIDE VIEW



BACK VIEW

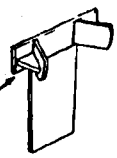


head positioner

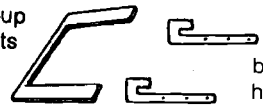
Important: Pad it well.

Wedge adjusts angle of head piece.

Bottom slides into slot on rear of chair.



swing–up armrests

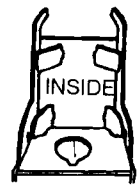


brackets to hold armrests

padded hip and shoulder positioners

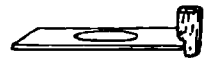


Tabs fit into slots in the wheelchair back and seat.



potty bowl holder with leg separator

Pull out to empty potty



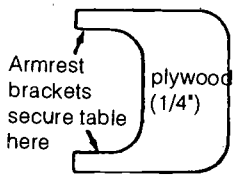
potty bowl



Tree branch holds stiff legs apart.

lap table

The lap table should be cut to fit closely around the wheelchair sides. The same wooden brackets for the armrests keep this table in place.



If the table wobbles, you can use small slats to strengthen the table. If the knee separator is made a bit higher, the table can rest on top of it and prevent any dips.

SPRINGS FOR ALL 4 WHEELS

This plywood wheelchair has a springy ride. Old inner tube rubber strips connect the rear wheel axle to the wood strips holding the front caster wheels. These wooden strips should be strong enough to withstand the springy motion of the front casters.

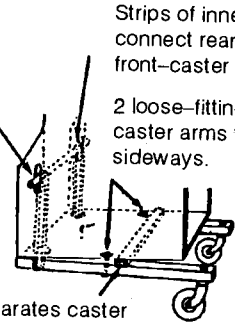
Special cut–away a lots allow the rear axle to move up and down freely. Other cut–away slots in the bottom of the wheelchair allow for the inner tube strips to be wrapped around the wooden caster strips. The tighter the inner tube strips are wrapped, the less bouncy the ride becomes.

To build your own strong rear hub and axle, see p.751. If you want to use hubs from bicycle wheels, see p.723.

Strips of inner tube connect rear axle to front–caster arms.

A long hole here allows back axle to spring up and down.

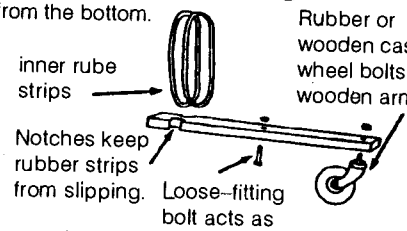
2 loose–fitting bolts keep caster arms from moving sideways.



Wood strip separates caster arm from the bottom.

Rubber or wooden caster wheel bolts to wooden arm.

inner rube strips

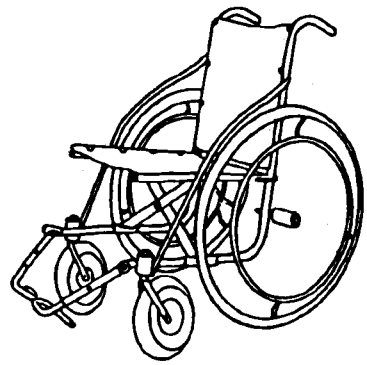


Notches keep rubber strips from slipping.

Loose–fitting bolt acts as pivot

WHIRLWIND STEEL TUBE WHEELCHAIR

The whirlwind (ATI–Hotchkiss) wheelchair is a very strong lightweight folding chair. On rough ground it rides more easily and lasts longer than more costly factory–made chairs. If it breaks, it can be fixed by the neighborhood metal worker. It is narrow and helps the rider to move about crowded rooms.

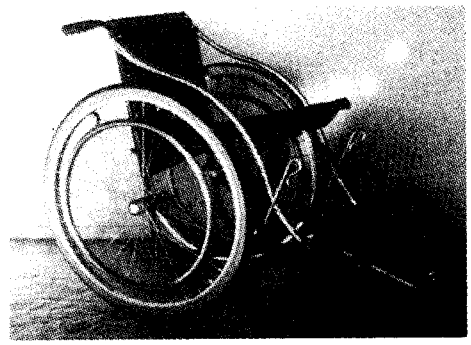


The frame of this chair is made of thin–wall steel tubing that is easy to shape by someone with basic mechanical and welding skills. It can be build in about 4 days in a small metal working shop. More than 10 groups of disabled mechanics throughout Latin America are building this wheelchair – often at less than a quarter the cost of imported wheelchairs.

Most materials for this chair can be obtained locally. It uses standard 24" (or 26") bicycle wheels. The extra strong hubs (see p.751) use standard small machinery bearings (which can often be obtained used for free or at low cost from electric machinery repair shops). The axles are 5/8" (1.6 cm.) steel bolts. Seating is canvas (heavy cloth). If the small front wheels are not available, you can make them out of wood (see p.723 and 744).

The curved fender bar that follows the shape of the tyre makes transfers easier. The lightweight folding footrests are narrow at the front, for moving more easily in crowded spaces.

Plans for making hubs, casters, and brakes are on the next page. Complete plans for making this wheelchair are in the book ***Independence Through Mobility*** (see p.730). The book is essential for anyone planning to build this chair.

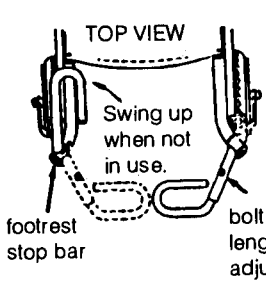


Model with wooden front wheels.

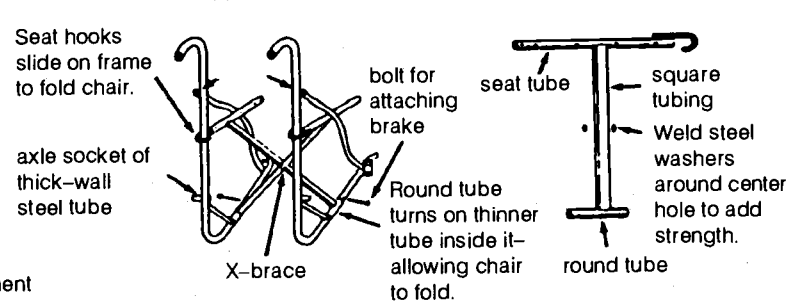
MATERIALS NEEDED

- thin–wall tubing (from 1/2" to 1 1/4")
- thick–wall tubing (5/8" inside diameter)
- thick canvas or nylon cloth (2 meters)
- square tubing (thin–wall)
- bicycle rims and spokes (24" or 26" diameter)
- caster wheels (2)
- used sealed bearings (8)
- re–bar steel (3/8" round)
- flat bar steel (1/6" x 3/8
- axle bolts (4) (1" diameter, 16 upholstery)
- washers (4) (1" diameter, 16 upholstery)
- screws (8 upholstery)
- machine screws (8) (1/4" x 1 1/2")
- paint or chroming chemicals
- bronze welding rod, flux
- bicycle tires and inner tubes (24")

FOLDING FOOTREST



X–BRACE

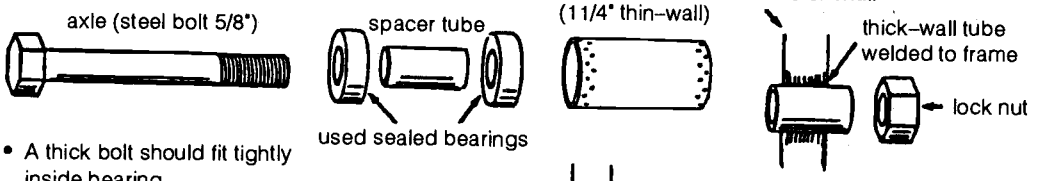


For a photo of this chair, see p.652.

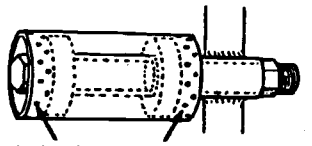
DETAILS OF HOW TO MAKE WHEELCHAIR PARTS

(can be used with many wheelchair designs)

HEAVY-DUTY WHEEL HUBS



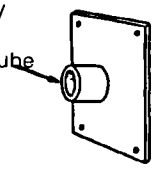
- A thick bolt should fit tightly inside bearing.
- Bearings should fit tightly inside outer steel tube.
- Carefully mark and drill the outer steel tube for spoke holes.
- Spacer tube fits over axle bolt and holds bearings against spoke heads.

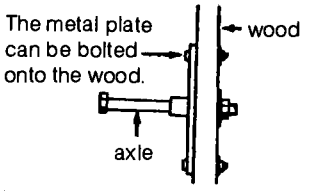


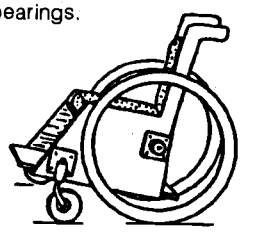
Note: Used sealed bearings with a 5/8" inner diameter can often be obtained free or at low cost from electrical tool and appliance repair shops. These used bearings often last longer than standard wheelchair bearings.

To attach the heavy-duty hub to a wood chair, you can weld the thick-wall tube to a metal plate.

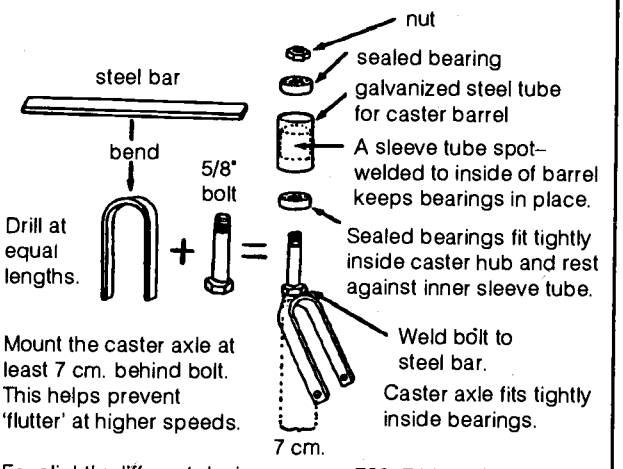
The bigger the plate is the stronger the mount.







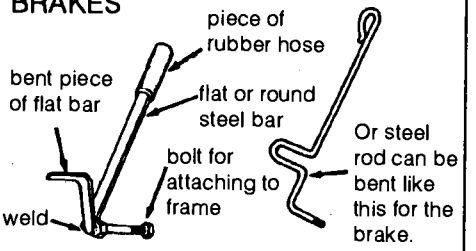
CASTER FORK AND HUBS

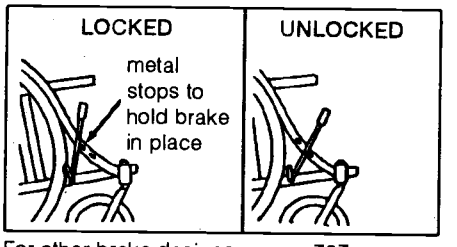


Mount the caster axle at least 7 cm. behind bolt. This helps prevent 'flutter' at higher speeds.

For slightly different designs, see p. 723, 744, and 747.

BRAKES



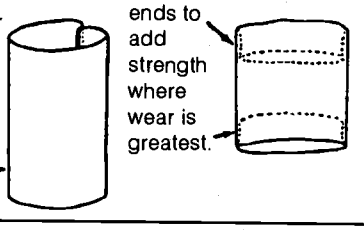


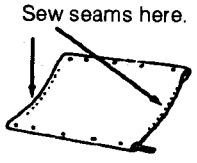
For other brake designs , see p.727.

SEAT AND BACK MADE OF CANVAS (strong cloth)

Cut canvas twice as wide as seat or back, allowing 4 cm. extra on sides (for seams) and at least 20 cm. longer on length.

Sew canvas into a tube.





Drill holes and screw rods to frame.



CAUTION : Measure carefully. On a folding chair, the width of the seat and back control the width of the chair.

For designs of other wheelchair parts, see the following pages:

wheels : 720, 722, 744, 747
tires : 722
cushions: 234, 735
footrests: 726, 744, 747, 749, 750
axle mounts: 723, 724, 743
handrims: 727
seats and backs : 721, 743, 744, 745, 747, 748
armrests: 725, 749

Examples of locally made wheelchairs





The plywood wheelchair on p. 748, with the armrest in place (left) and swung back (right).



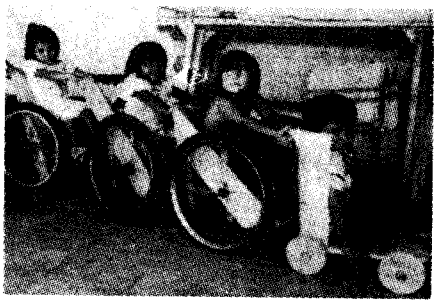
A plywood wheelchair for a child with cerebral palsy with inner tube stretching aids to gently pull his feet and strengthen his severe knee contractures.



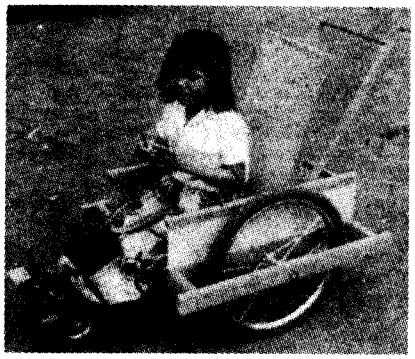
A bamboo hand-powered tricycle made at Viklang Kendra (People"s Village), Allahabad, India.



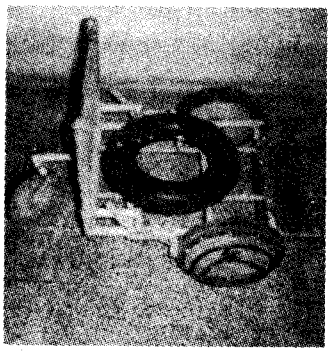
A wheelchair made completely of paper, including the wheels. Paper is glued together using rice flour in water (Zimbabwe).



A wood design of the wheelchair on p. 745, two AHRTAG wheelchairs, and a 'trolley' made from half of a plastic bucket and wood wheels.



A wood wheelchair in Thailand. The bicycle wheel axles are supported on both sides to keep them from bending.



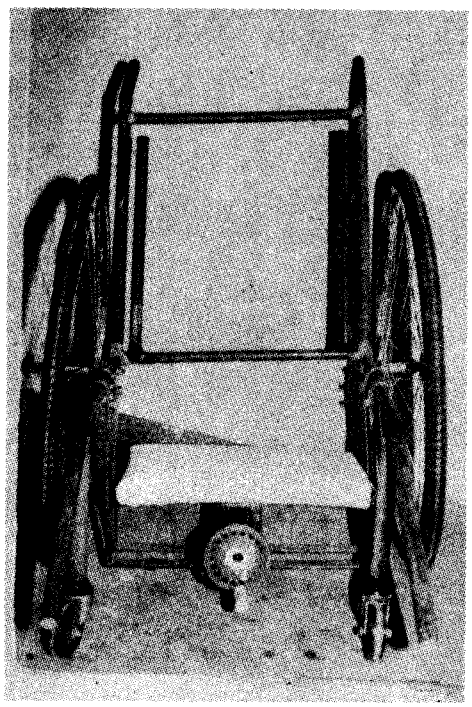
A metal frame, wood wheel 'trolley' in Bangladesh (see p. 696.) The rubber tube serves as a cushion and also as a toilet seat.



This trolley, also from Bangladesh, use a cushion made of coconut fiber covered with rubber (see p. 233).

For more examples of wheelchair designs, see p.70, 96, 110, 221, 272, 356, 419, 524, 535 and 638.

Wheelchair :



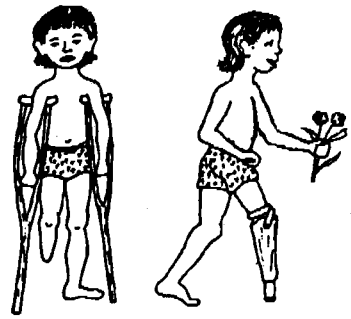
This self-help wheelchair was designed at Seva-in-Action to help disabled persons to move independently in the rural areas of Bangalore district. The design is based on the felt needs of families with grown-up disabled children and disabled people themselves. While the ordinary wheelchair helps a person to move from one place to another, often he needs help to get in or out of the wheelchair. So a ordinary hand turning jack was attached to the seat of the self help wheelchair. A disabled person can operate the jack and adjust the seat to get on and off the wheelchair independently. The self-help wheelchair can be made and repaired by the local rural technical in the villages.

NOTES:

CHAPTER 68

Artificial Legs

Artificial legs can be (and often are) made at home or in village shops. How well they work and how natural they look depend on many things, including costs, skills and materials available.



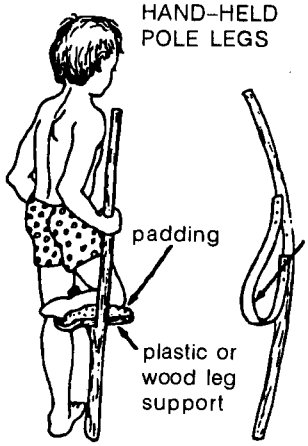
Even a simple artificial limb can make a big difference.

BELOW THE KNEE

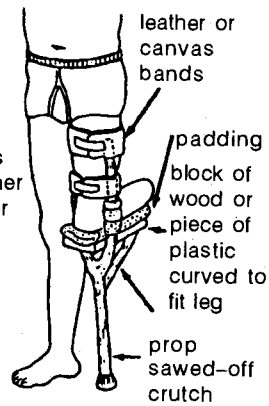
The most common leg amputation is below the knee. A leg that has been amputated **halfway between the knee and ankle** works best for walking with an artificial ***limb.*** Here are some examples of artificial limbs from simple to more complex.

WITH THE KNEE BENT

HAND-HELD POLE LEGS



'SAWED-OFF CRUTCH' LEG

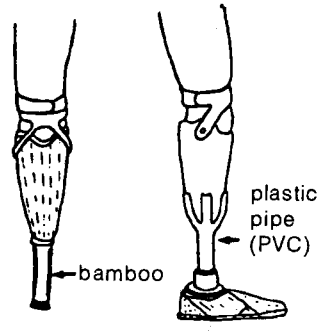


CAUTION: Limbs like these 3 are quick and easy to make, but **they cause knee contractures. As a result, the knee cannot be easily straightened** to fit a better more useful limb. **Bent-knee limbs should only be for temporary or emergency use. Do exercises everyday** to keep the knee straight and strong (See p.272 and 273).

WITH THE KNEE STRAIGHT

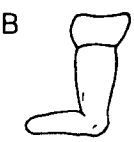
BAMBOO AND PLASTER LEG (See p.758)

PLASTIC PIPE LEG WITH FOOT (See p.762)



These limbs are better because the knee has full range of motion. Walking is easier and more natural. However, **the person's weight must be supported evenly over the entire stump, not only at the end of the stump.** (See p.761)

Positions for FITTING A LIMB



BAD

will only work with a bent knee limb



DIFFICULT

knee does not straighten fully



GOOD

knee straightens completely.

Exercises to strengthen and straighten the leg

From the time a leg has been amputated until a limb is fitted, daily exercises are needed to keep the hip and knee ***muscles*** strong and to avoid contractures. If weakness and contractures already exist, these should be corrected as much as possible before a limb is fitted. Exercises are discussed on p.272 and 273.

AVOID CONTRACTURES



Contractures here and here need to be straightened before a standard limb can be fitted.

How soon can an artificial limb be fitted?

Children born without a foot or part of a leg (or legs) can be fitted with an artificial limb as early as 10 or 12 months of age.

A child whose foot has been cut off can and should be fitted with a temporary limb **as soon as the wound has healed. However, be very careful not to injure or put any pressure on the new scars or end of the stump**

Note: On a very young or fat child, it may be difficult to fasten the limb firmly to the knee (the bones may not stick out enough). Straps to a waistband and even over the shoulder may be needed.

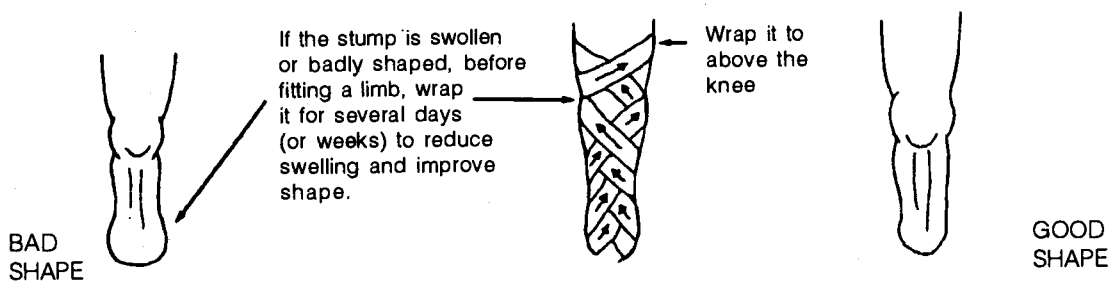


Temporary limbs–when to use them and why

Because a stump usually shrinks and changes shape in the first weeks after a limb is fitted, it is often wise **first to fit a low–cost, temporary limb**. This is especially true if the amputation is new or the stump is swollen. A better–looking, more permanent limb can be made after 4 to 6 weeks, or when swelling is gone.

Preparing the stump

In the first weeks or months after an amputation, the stump tends to swell up. The swelling may in time lead to a club–shaped, deformed stump, which is difficult to fit with an artificial limb. For this reason, **it is important to wrap the stump with elastic bandage from the time the leg is cut off until a limb is fitted**, or at least until there is no more sign of swelling. Instructions for wrapping the stump are on page 271.



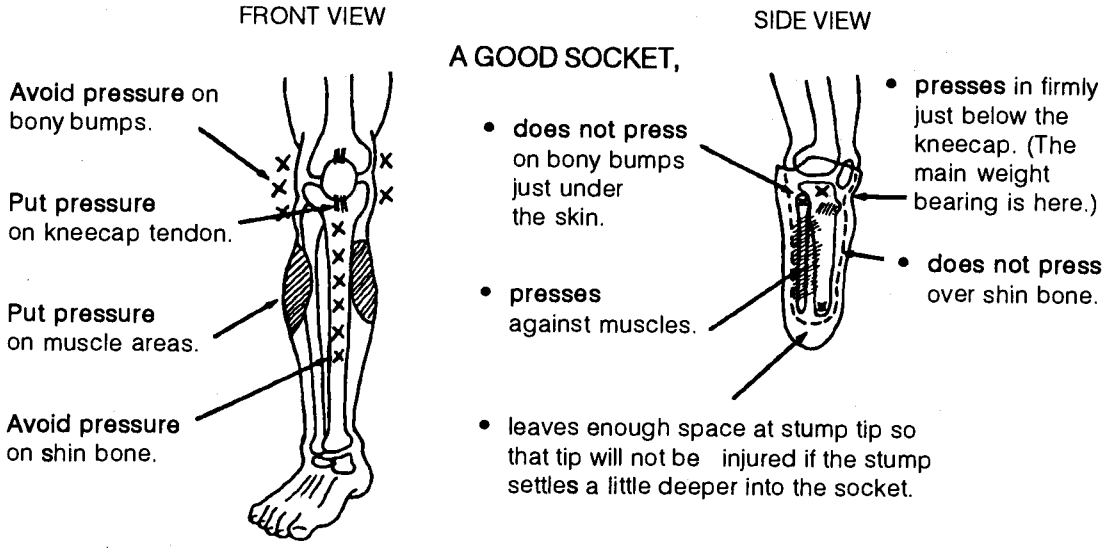
Note: When the person is not wearing the artificial leg, he should also wear an elastic bandage to control the stump shape.

The art of limb making

Making artificial limbs that fit and work well is both a science and an art. If possible, try to learn from a skilled limb maker. 'On–the–job" training for even a few days can make a big difference.

Before starting to make an artificial limb, STUDY THE PERSON'S LEG.

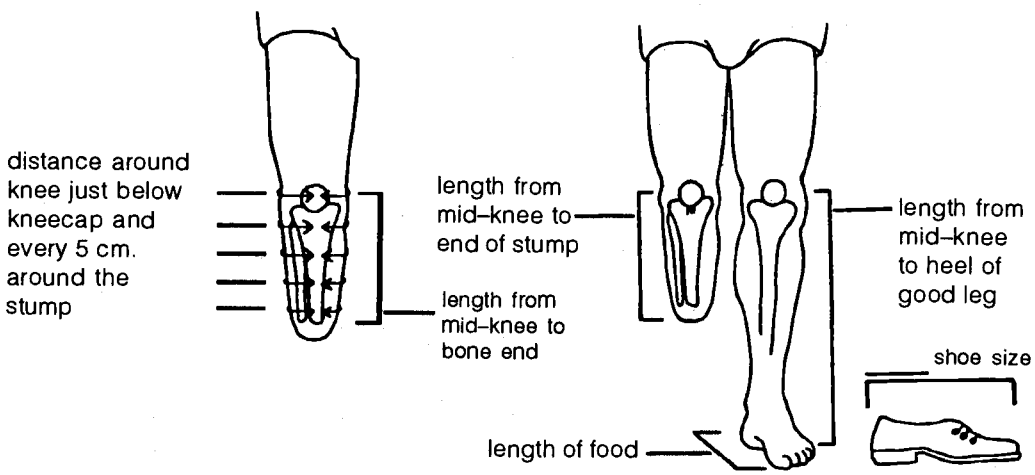
A good fit of the socket on the stump and at the knee is one of the most important – and difficult – parts of limb making. It helps to have an understanding of the bones and muscles in the leg.



Before beginning, study the person's knee and stump carefully. Note the positions of the kneecap, the bony bumps on the sides of the knee, and the shin bone.

MEASUREMENT YOU MAY NEED FOR A BELOW-KNEE LIMB

(Copy this chart and use it to record your measurements.)



Note: For the plaster and bamboo limb, only lengthwise measurements are needed.

Note: The artificial limb should be the same length or just a little shorter than the other leg.

PLASTER AND BAMBOO BELOW–KNEE ARTIFICIAL LEG

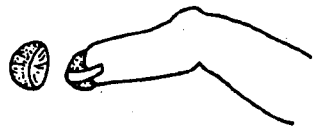
This simple, low–cost leg was developed for refugee amputees in Thailand by Operation Handicap Internationale. It is most useful as a temporary limb for learning to walk. However, if the inner (plaster) part of the socket is made with waterproof glue, or is protected from getting wet, the leg can last for a long time.



A village rehabilitation worker fits a young man with a bamboo limb. (PROJIMO)

Steps for making the plaster socket

1. Make a thick 'cup' or 'cap' of sponge or folded cloth and tape it over the end of the stump (to give it a little extra length).



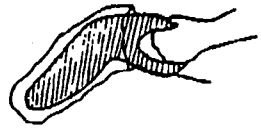
2. Put a thick, tight–fitting stocking–without seams if possible over the stump and knee. (Several thin layers of stocking can be used instead of a thick one.)



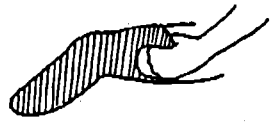
Putting holes near the top of the stocking makes it easy for the child to pull it up tight against the skin while the cast is put on.



3. Put a thin plastic bag over the stocking.



4. Put a thin cotton stocking or stockinette over the plastic bag and also pull tight to avoid wrinkles.

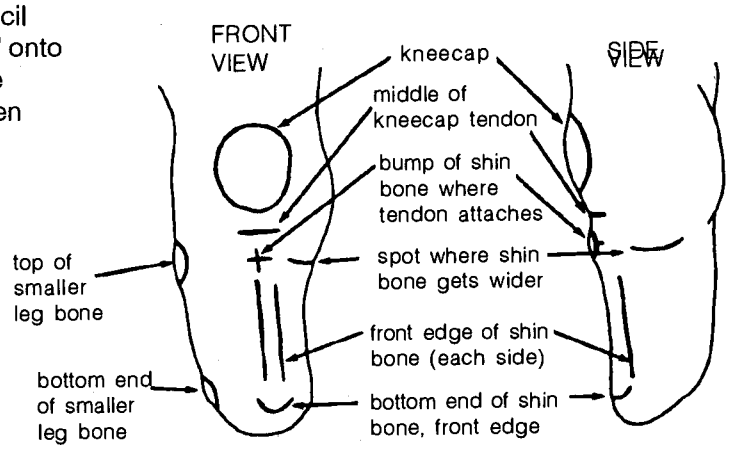




Note: If you do not have a stocking, you can mold the socket directly on the stump Shave any hair off the stump and cover it with vegetable oil (for example, coconut or palm oil).

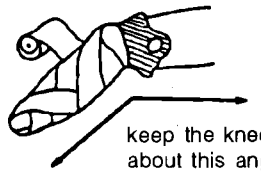
5. With the stocking stretched tight, mark the important places with a 'grease pencil'. The pencil marks will 'print' onto the inside of the plaster cast when it is removed.

Mark all these places:



6. Wrap the stump and knee with plaster bandage. **Be very careful to put the bandage on evenly and smoothly.** (Elastic plaster bandage works best, but is very costly. To reduce costs you can make your own plaster bandages for casting. See p.693).

Cast the knee with the stump slightly bent.



keep the knee at about this angle

MAKING THE PLASTER WATER-RESISTANT

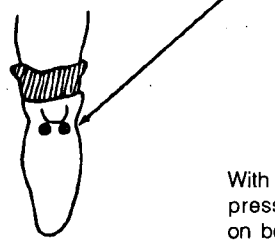
The plaster cast of the stump will become the inner layer of the socket of the bamboo limb. So it should be strong and waterproof. To make the cast stronger and water-resistant, wet the plaster bandage with glue instead of water.



Use a water-base glue that is water-resistant when it dries.

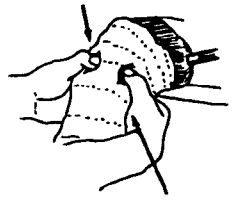
Note: If the plaster cast is to be used only as a mold for making a leather or resin socket, use water, not glue.

7. As the plaster dries, hold the stump firmly below the knee.



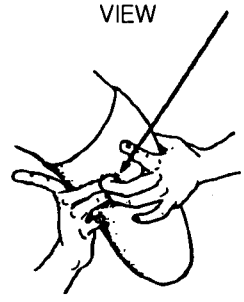
Press your thumbs on each side of the tendon just below the knee cap.

FRONT VIEW



With the ball of the hand, press gently on the muscles on both sides of the leg.

BACK VIEW

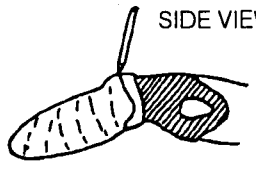


With the 2 middle fingers of each hand, press into the hollow behind the knee.

Hold the stump like this until the plaster is hard enough to hold its shape.

8. When the cast becomes hard, mark where to cut the top edge (see below).

SIDE VIEW



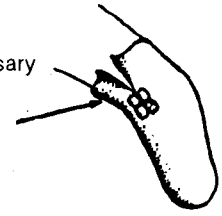
BACK VIEW



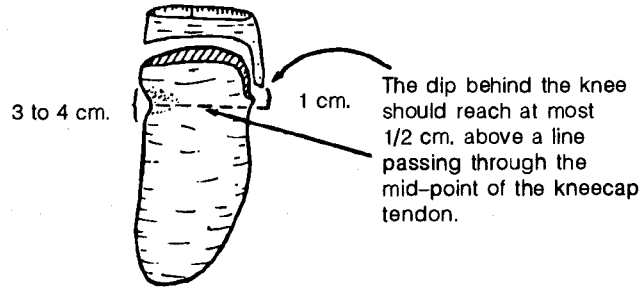
9. To remove the cast, roll the stocking over it. Put your hands over the pressure points (as shown above.) Have the child wiggle the stump as you gently pull off the cast.



It may be necessary to cut the cast behind the knee, like this, to get it off.

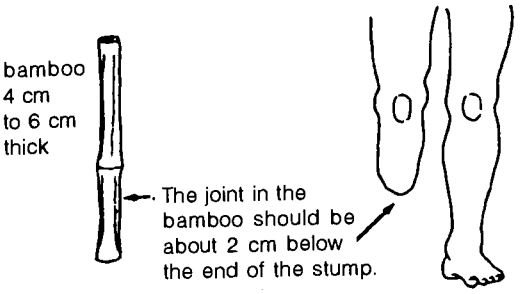


10. Cut the cast along the line you drew.

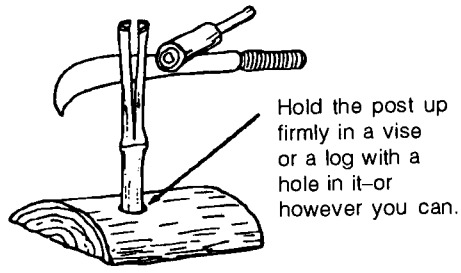


Preparing the bamboo post

1. Select a piece of strong, green bamboo a little longer than the good leg from the knee to heel.



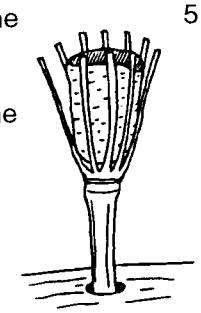
2. Split the bamboo to a little below the level of the stump end. Split into thin strips–each about 3/4 cm wide.



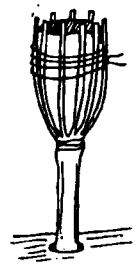
3. Remove the softer inner layer from each of the thin strips.



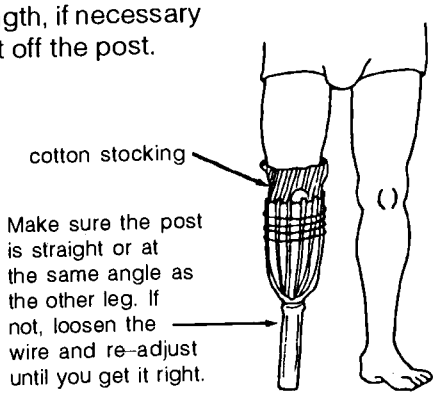
4. Spread the bamboo strips around the plaster socket.



5. Position the socket as correctly as you can. Then, with a thin wire, wrap the bamboo tightly against the socket.



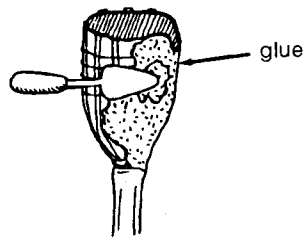
6. Put the limb on the stump and have the child stand on it. Check the length, if necessary cut off the post.

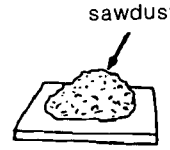


Note: If child uses a shoe or sandal, be sure to have her wear it when measuring the height of the limb.

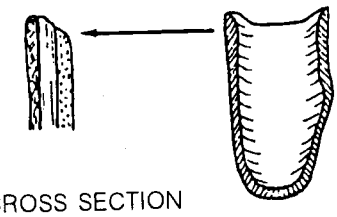
7. After trimming the tops of the bamboo strips, cover the outside of the socket with several layers of glue, sawdust, and gauze bandage.

- Brush on one layer of glue.
- Press sawdust on the glue (with gloves)
- Wrap tightly with gauze bandage. Let it dry.
- Repeat 5 or 6 times



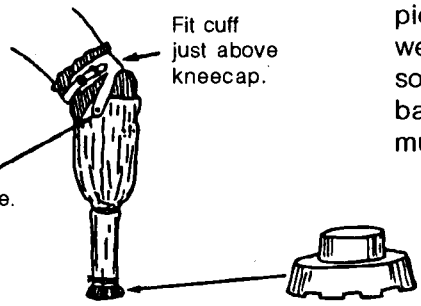


8. Smooth the outside of the socket with sandpaper. Also smooth and round the inner edges at the top.



CROSS SECTION

9. Make a 'cuff' to hold the limb on. (If attached correctly, it should also help keep the knee from over-straightening.)

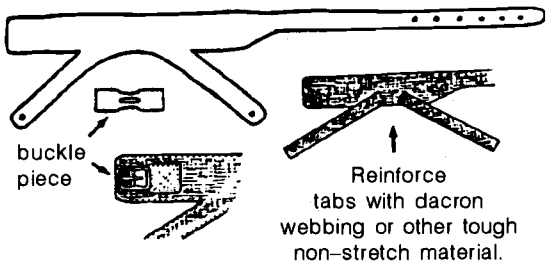


10. Make a rubber 'heel' – a piece of thick truck tyre works well. If you can, cut the tyre so that a 'plug' fits inside the bamboo. Cut off bamboo as much as the heel is thick. (Be sure to allow for height of sandal or shoe on other foot.

Design for knee cuff

Use strong leather and line it on inside with soft smooth leather It should be a few cm. longer than the distance around the knee.

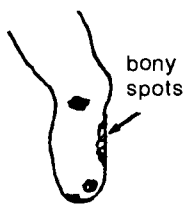
Glue layers of leather and webbing together with rubber cement and sew at edges.



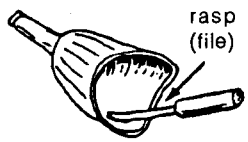
(For other ways of holding the limb to the stump, see p. 756.)

11. Have the child stand and walk on the limb for several minutes. Then remove it and look for sore spots on the child's skin, or signs of too much pressure. Check especially over bony spots. An area that looks pale when the limb is removed and then turn red or dark, is a sign of too much pressure.



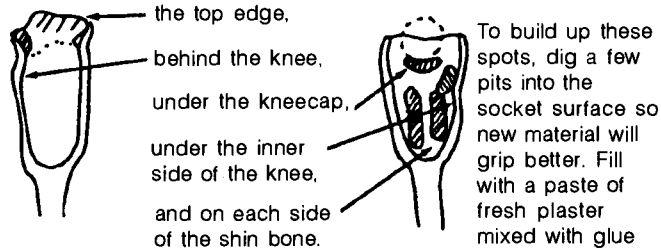


12. Scrape shallow pits into the socket from the inside, at the points where it presses over bones. You may also need to build up around the area where pressure occurs.

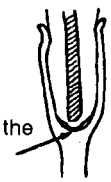


(To help you find the right points, it helps to have marked 'bony spots' before casting. They will then be 'printed' inside the socket–see p. 758.)

If stump presses on bottom of socket, you may need to build up

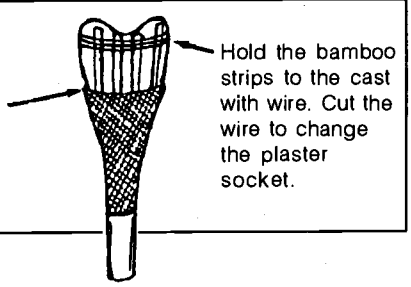


To build up these spots, dig a few pits into the socket surface so new material will grip better. Fill with a paste of fresh plaster mixed with glue



If socket presses on the end of the bone, scrape out a hollow here

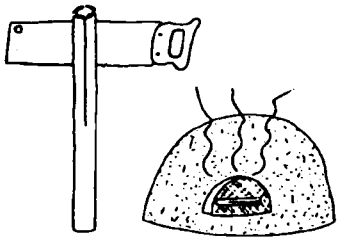
During the first few weeks of using an artificial limb, the stump becomes smaller, and several changes in limb size may be needed. To save time, use a shorter bamboo post so that the plaster socket can be replaced several times with new, smaller ones.

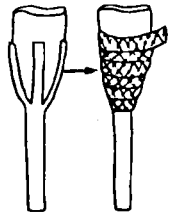


Artificial leg using PVC plastic pipe instead of bamboo

Where plastic PVC water pipe is available, it can be used instead of bamboo. Use a 3 cm. (11/4 inch) thick-walled PVC.

1. Measure the tube the same as bamboo, and cut it to form 4 strips.
2. Heat the PVC in an oven until it gets a little soft.
3. Fit the hot PVC around the socket piece and wrap it tightly with a long strip of cloth or rubber until it cools.
4. Fasten PVC firmly to socket with wire or rivets (or both). It is best to attach it temporarily with wire and to have the child try it before you fix it permanently.
5. Cover with sawdust and glue, or with resin-base casting bandage (very expensive) or with fiberglass and resin (also expensive).





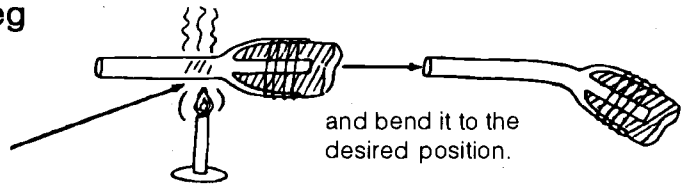




Note: For a stronger, water-resistant limb, the socket can also be made with resin-based casting bandage. But this is also expensive.

Adjusting the PVC leg

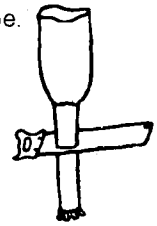
After the child tries on the leg, if the angle seems wrong, you can gently heat the PVC near the stump,



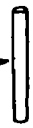
and bend it to the desired position.

Lengthening the PVC leg to allow for growth of the child

1. Cut through PVC pipe.

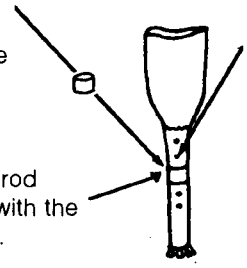


2. Cut a strong hardwood rod or plastic tube that just fits inside the PVC.



3. Cut a ring of PVC pipe as long as the additional leg length needed. (Make it a little extra long to allow for more growth.)

4. Put the wood rod inside the PVC with the new ring of PVC.

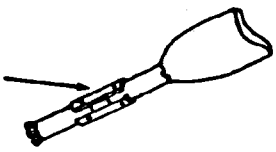


5. Drill holes and screw or bolt leg together tightly.

6. When an even longer limb is needed, replace the short ring with a longer one.



7. If necessary, to make the joint stronger, cut a piece of PVC lengthwise, heat it, put it over the leg tube, and attach it tightly.



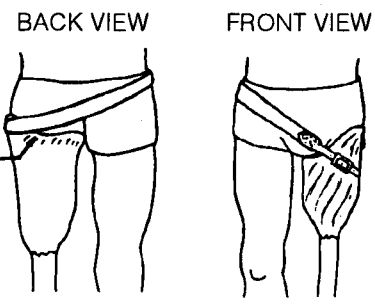
IMPORTANT: For both below-knee and above-knee limbs, try to **line up the limb** as well as possible so that its angle is similar to the other leg and 'feels right' when the child stands and steps. Often this requires repeated tries and adjustments. **Getting the limb to line up right is the key to successful limb fitting.** It helps to learn this from someone skilled at fitting limbs.

ABOVE–KNEE ARTIFICIAL LIMBS

Children who are growing quickly need a low–cost limb that can be easily replaced or lengthened. Small children usually learn to walk well with a straight leg limb that does not have a knee joint.

1. **A bamboo or PVC plastic tube above–knee limb** can be made in much the same way as for the below–knee limb.

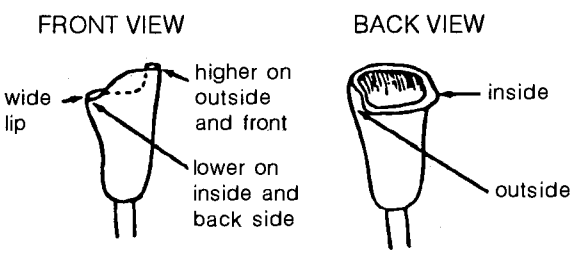
The top edge of the socket should be rounded to form a wide lip on the back, where the buttom can sit. Weight bearing should be on the buttom bone and over the entire stump–and not just on the end of the stump.





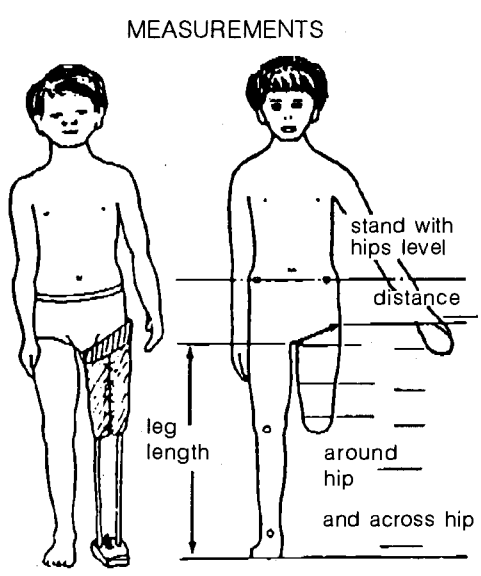
Note: In some countries, thin plastic cuffs the right shape for socket tops can be purchased in different sizes from ***orthopedic*** suppliers. They can be placed around the leg before casting and can be re–used. Ask for prefabricated ishial weight. bearing cuffs',

Best shape for top of socket:

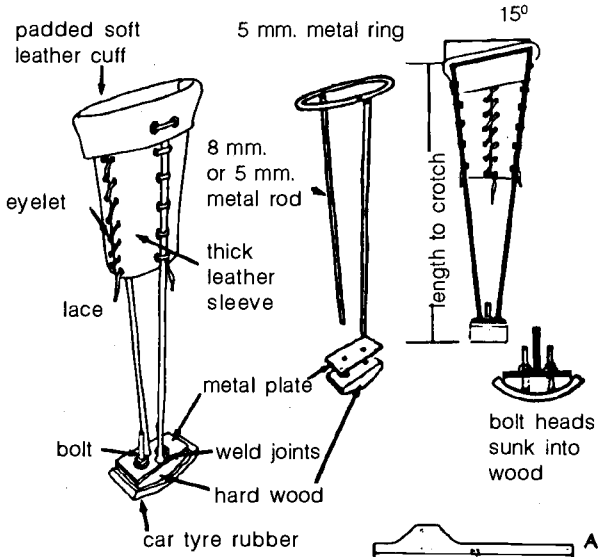


Make the top of the socket somewhat **square.** You can reshape the wet plaster a little while it is still on the stump. or just after you take it off.

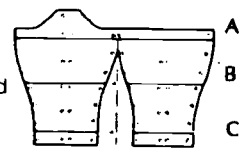
2. **A leather and metal rod limb** (adapted from ***Simple Orthopaedic Aids,*** see p. 774).



Note: The socket is open at the bottom of the stump. This makes it cooler than the one above. and also allows for growth.



To make sleeve, draw on paper a design like this based on A.B. and C stump measurements. Then copy onto leather and cut it out

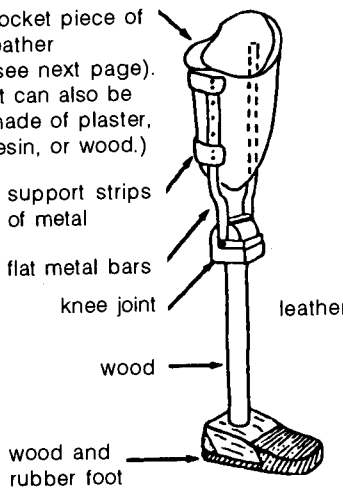


Above-knee limb with knee joint (for older children and adults)

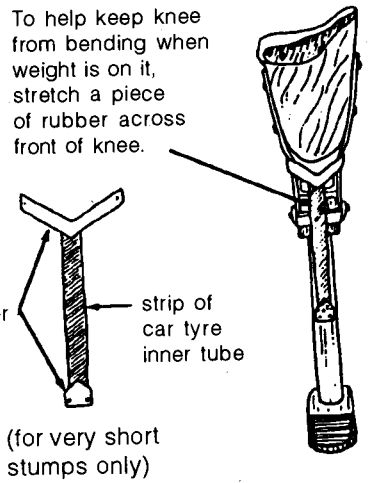
Adapted from the OHI Manual: *Simple Above-knee Prosthesis Manufacture.* (Write for the complete manual. For Address, see p. 774.)

Note: This is a simple design for a knee joint. Knee joints that work well are hard to make and you may need to experiment a lot. Perhaps you can re-use a joint from an old limb that is not being used.

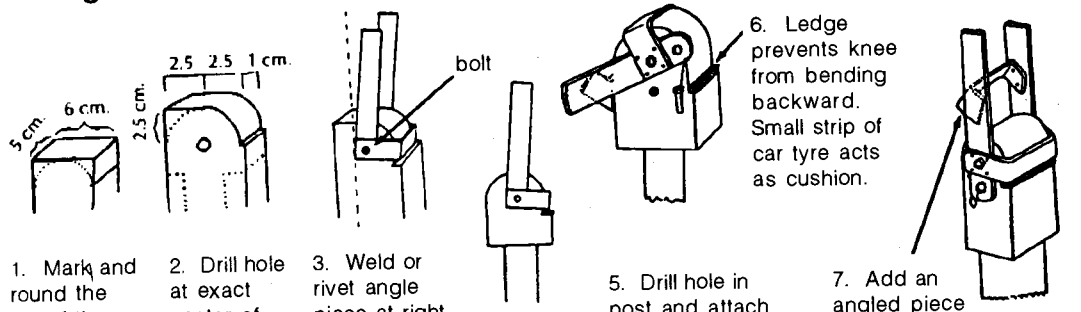
SIDE VIEW



FRONT VIEW



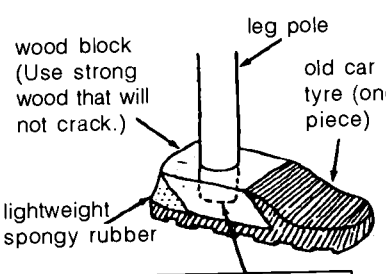
Making the knee joint:



1. Mark and round the top of the post.
2. Drill hole at exact center of circle.
3. Weld or rivet angle piece at right angle. (Use flat metal bar.)
4. Round back of post.
5. Drill hole in post and attach bolt with wire (to lock knee straight, when necessary).
6. Ledge prevents knee from bending backward. Small strip of car tyre acts as cushion.
7. Add an angled piece to allow joint to stop in a squatting position.

FEET

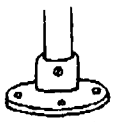
Putting feet on artificial legs makes them look better (with shoes, sandals, or boots). Also, the wide base helps prevent the leg from sinking into mud or sand. A well-made, flexible foot can make walking easier. Here are 2 possibilities.



Note: By putting the pole through the foot, if the foot breaks off the person can keep walking.

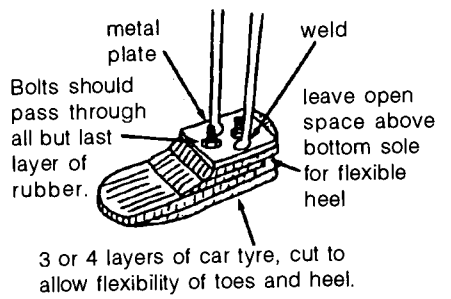


The sponge rubber over the heel and toe lets the foot bend for smoother walking.



To mount a foot on a plastic PVC tube, use a metal pipe base like this.

A foot can also be made for a metal-rod leg. Here is one possibility.



Artificial Bamboo–cane limb

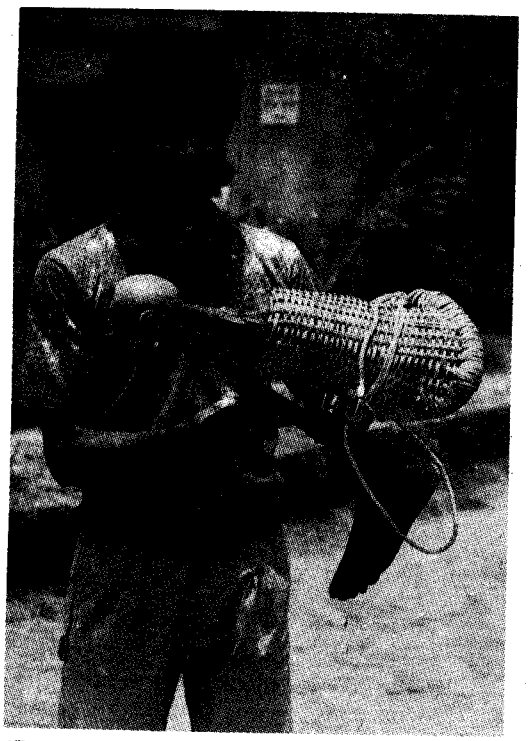
Low cost and comfortable artificial limbs made with Bamboo–cane are manufactured at Viklang Kendra. Joints made of coconut shells prevent buckling.



(Above knee limb)



(Coconut shell Joint)

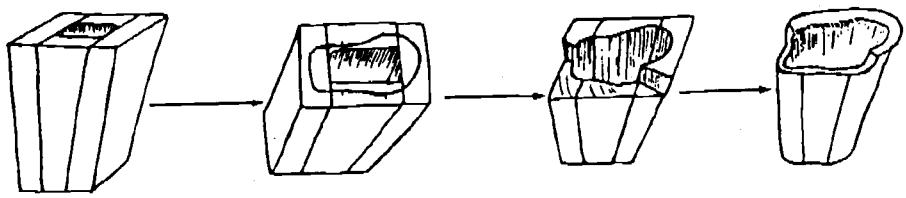


(Below knee limb)

OTHER WAYS OF MAKING ARTIFICIAL LIMBS

Wooden legs

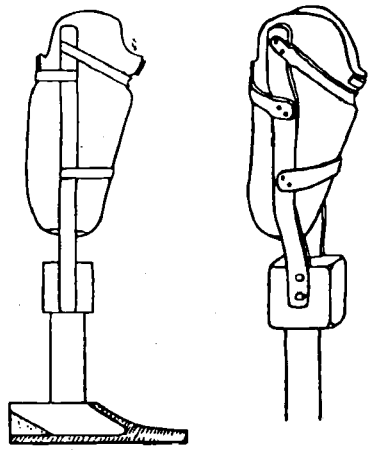
The oldest, traditional way of making artificial limbs is to make the socket out of wood.



This is best learned from a skilled craftsperson. A book that describes the method step-by-step is ***Manual of Above Knee Wood Socket Prosthetics*** (see reference, p. 774). Unfortunately, the methods described are complex and require a lot of special equipment. However, perhaps they could be simplified. (We have not tried this method.).

Leather socket: Self-adjusting prosthesis

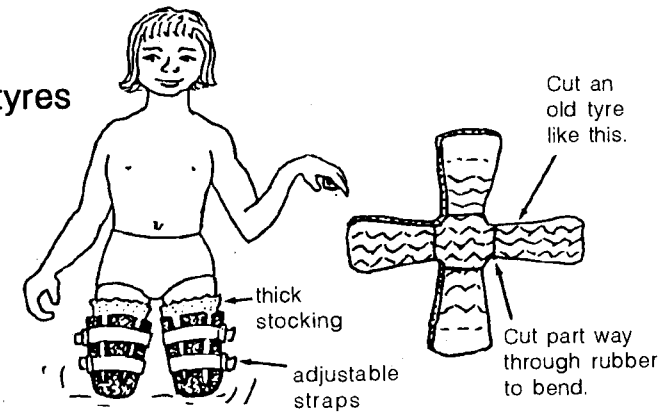
This method uses flat metal bars, a wood post, and a thick, firm leather socket. To form the socket, wet leather is stretched over a plaster mold of the stump. Methods are clearly and simply described in ***Simple Below-knee Prosthesis Manufacture.*** (See reference, p. 774.)



A leather socket has several advantages. Leather is available almost everywhere, is more comfortable in hot weather, and can easily be adjusted to the stump as it becomes smaller. Also, leather is soft and easily takes the shape of the stump, and therefore self-corrects molding mistakes.

Stump protectors from old tyres

For a child with both legs amputated above the knee, short artificial limbs or even simple 'stump protectors' may allow her to move about easier than long leg limbs.

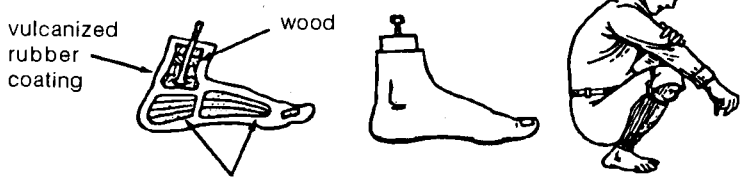


Jaipur limb

The 'Jaipur limb' was developed in Jaipur, India to meet the need for a limb that would (1) allow working 'barefoot' in rice paddies, (2) look like a real bare foot, (3) bend at the foot in all directions enough so the person can squat easily and walk firmly on uneven ground, and (4) be low cost and quick to make.

The foot is made of wood and sponge rubber and then 'vulcanized' (heat molded) with rubber, using a metal mold. The rubber gives the foot its life–like form and color and makes it strong and waterproof.

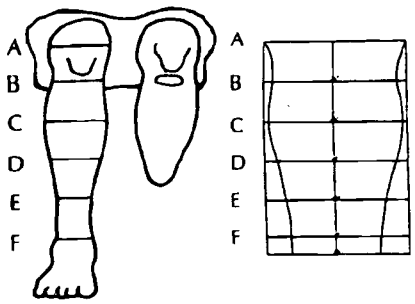
THE JAIPUR FOOT



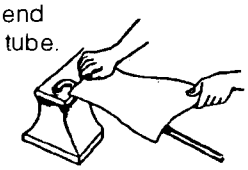
The limb is made of SHEET ALUMINUM.

1. Take measurements of normal leg.

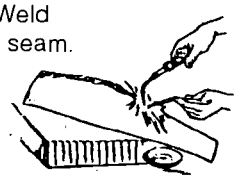
2. Mark a sheet of aluminum and cut out leg form.



3. Bend into tube.



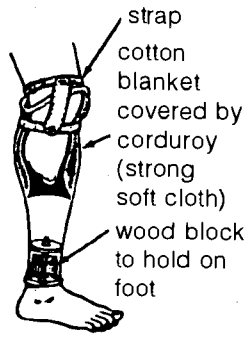
4 Weld the seam.



5. Hammer tube into shape of leg. With repeated tests, fit it to the knee just right.



6. Attach knee strap and foot.

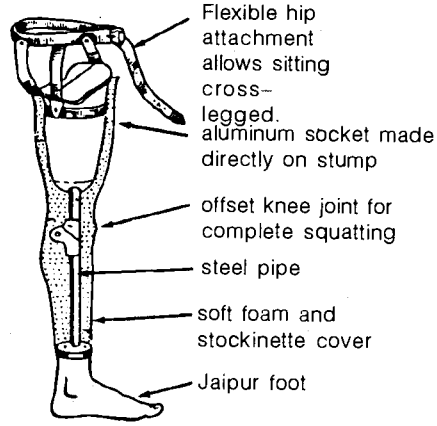


(Total cost for the below–knee limb can be less than US $20.)

To make the Jaipur limb requires a lot of skill as well as special equipment. But once a shop is set up and persons trained, the limb can be made at very low cost, and fitted very quickly (one hour from the first measurements until the person walks away on his new limb). For instructions, contact Rehab Centre, SMS Medical College, Jaipur 302004, India.

Ideas for a limb–making shop. On p. 629 there is a description of the OHI prosthetics shop in Thailand, where amputee workers make the bamboo and above–knee adjustable limbs shown in this chapter.

JAIPUR ABOVE–KNEE DESIGN



NOTES

REFERENCES

(Where to Get More Information)

Here we list selected books, papers, and educational materials that you may want to obtain for more information on disabilities and rehabilitation. Where possible, we have included an ordering address and price. The materials are arranged more or less as the subjects are covered in this book. Most were used in putting together this book, and some we found clear and useful, while others are more complicated. We have therefore included a few comments about each book, and have marked each entry with 1 to 5 plus (+) marks:

+++++ = Very highly recommended. If you are working with children whose needs relate to the subject area of this book, get the book if you possibly can.

++++ = Highly recommended. You can learn a lot from this material to supplement what is covered in ***Disabled Village Children.***

+++ = Many useful ideas, with more complete coverage or detailthan in ***Disabled Village Children.***

++ = Some important additional information.

\+ = Some useful additional information, but not essential.

✓=This means that in this book we have used or adaptedquotes, ideas, or pictures from the books marked with this symbol.

DISABILITY AND REHABILITATION-GENERAL

+++ Bleck, Eugene and Nagel, Donald Physically ***Handicapped Children: A Medical Atlas For Teachers.*** Grune and Stratton, Inc.Orlando FL 32887.
Useful information on a wide range of physical disabilities. Good illustrations. Helpful in diagnosis.✓

++ Glorya Hale, editor. ***The Source Book For the Disabled.*** W.B. Saunders Company, W. Washington Sq., Philadelphia, PA 19105, 1979, 288 pages.
Good ideas-but mainly for the middle class in developed countries.✓

+++ Hardinge, Elizabeth A., and Wilson, Patricia M.P. ***A. Manual of Basic Physiotherapy for the Use of Nurses in Rural Hospitals***. Tear Fund, 100 Church Rd., Teddington, Middlesex, TW 11 8QE,England, 1981, 162 pages.
Basic; clearly presented; some big words; very useful.

+++ Helander, Einar; Mendis, Padmani; Nelson, Gunnel. ***Training Disabled People In the Community*** World Health Organization,Distribution and Sales Service, 1211 Geneva 27, Switzerland, 1980, 650 pages.
Very basic information-Sometimes too basic. This latest edition has been improved, but it still takes a rather top-down, authoritarian approach. Language very simple. Many pictures. Part of a total plan for a 'community-based', government-directed program.✓

++ ***Childhood Disability: Prevention and Rehabilitation At the Community Level.*** Rehabilitation International/ UNICEF Technical Support Program, 432 Park Ave. South, New York, NY10016, 1982.
An adaptation of the WHO manual "Training the Disabled In the Community." Shortened and improved, with a focus on children.✓

++ Larson, Heidi, editor. ***Childhood Disability Information Kit.*** UNICEF, Kathmandu, Nepal, August 1983. Five booklets: 1) Hearing and Speech, 31 pages: 2) Mobility, 64 pages: 3) Child Development, 22 pages: 4) Learning and Behavior, 39 pages: 5) Vision, 16 pages.✓
Attractive, simple introduction.✓

+++ Werner, David. ***Project PROJIMO.*** The Hesperian Foundation, PO.Box 1692, Palo Alto, CA 94302, 1983, $4.00.
A 65-page photographic report on the villager-run rehabilitation program in Mexico.✓

++ Ludins-Katz, Florence and Katz, Elias. ***Art and Disabilities.*** Institute of Art and Disabilities, 2839 Ashby Ave., Berkeley, CA 94705, 1983, 235 pages.
Ideas for starting an art center for disabled people. Materials,equipment, aids, and instruction needed for many crafts and art forms. ✓

+++ ***Booklist.*** International Disability Education and Awareness, 16 Bath St., Frome, Somerset BA 11 1DN, England, 1985, 12 pages.
Excellent list of basic books and distributors/publishers (mostly British).

PRIMARY HEALTH CARE

++++ Werner, David. ***Where There Is No Doctor.*** The Hesperian Foundation, P.O. Box 1692, Palo Alto, CA, 94302. 1977, 403 pages, $8.00.
Widely used handbook for village health workers and families on basic curative and preventive health care.✓

+++ Werner, David and Bower, Bill. ***Helping Health Workers Learn.*** The Hesperian Foundation, 1982, 632 pages, $8.00.
A 'people-centered' educational approach to health care.✓

++ Dickson, Murray.***Where There Is No Dentist.*** The Hesperian Foundation, 1983, 208 pages, $4.50.
Basic information on care of teeth and gums.✓

++++ King, Maurice and Felicity. ***Primary Child Care Book One.*** Teaching Aids at Low Cost (TALC), P.O. Box 49, St. Albans, Herts ALI 4AX, England.
Excellent health care guide for children.

POLIO

++++ Huckstep, R.L. ***Poliomyelitis: A Guide For Developing Countries-Including Appliances and Rehabilitation For the Disabled***. Churchill Livingstone, Robert Stevenson House, 1-3 Baxters Place, Leith Walk, EH I 3AF, Scotland, 1979, 279 pages.
Excellent and very complete. Includes braces, assistive equipment, rehabilitation, and information for hospital care and surgery. Well adapted to poor countries and community programs. Language fairly simple. Well illustrated.

CEREBRAL PALSY

+++++ Finnie, Nancie. ***Handling the Young Cerebral Child At Home.*** Dutton-Sunrise, 2 Park Ave., New York, NY 10016, 1975, 337 pages, $7.72 + $1.50 postage and handling.

Excellent, very complete and detailed information for home care. May be too much detail for some families-but a highly-recommended resource for a community program.✓

++++ Levitt, Sophie. *Treatment of Cerebral Palsy and Motor Delay.* Blackwell Scientific Publications, 8 John St., London, WCIN 2ES, England, 1977, 272 pages.

An advanced book, mostly on physiotherapy. Excellent information, but difficult language and presentation. Many good pictures."

MUSCULAR DYSTROPHY

+++ Booklets of aids and equipment for children with muscular dystrophy or paralysis. Well illustrated. Muscular Dystrophy Group of Great Britain and Northern Ireland. Nattrass House, 35 Macaulay Rd., London, SW4 0QP England.

SPINA BIFIDA

++ Swinyard, Chester. ***The Child With Spina Bifida.*** Spina Bifida Association of America, 343 Dearborn St., Chicago, IL 60604, USA, 1980, 52 pages, $1.50.

Contains some useful information with a lot of technical detail. Complicated language, but many terms are explained. ✓

+++ Welch, Collette. ***Spina Bifida and You: A Guide for Young People.*** Association for Spina Bifida and Hydrocephalus (ASBAH), 22 Upper Woburn Place, London, WC 1 H OEP, England.

This and 11 other publications on spina bifida are available from ASBAH. Some are excellent, others are not. Written for developed countries.

+++ ***Sex of Young People With Spina Bifida or Cerebral Palsy.*** ASBAH (See address above.)

Excellent.

SPINAL CORD INJURY

++ Bromley, Ida. ***Tetraplegia and Paraplegia: A Guide For Physiotherapists.*** Churchill Livingstone, 1981, 256 pages. Distributed in U.S. by Longman, I., 95 Church St., White Plains, NY 10601, $16.50.

Useful information on exercises, transfers, and weight shifting for pressure sore prevention. Some good illustrations. Rather technical. ✓

++++ Ralph K. Davies Medical Center. ***Spinal Cord Injury Home Care Manual.*** Castro and Duboce, San Francisco, CA 94114, 234 pages.

Excellent, very detailed yet very human advice on all aspects of home care and self-care. Long section on sexuality. Language at times a bit complex. Some good illustrations. Recommended for all programs working with spinal cord injury.✓

++ Goldfinger, Glen and Hanak, Marcia, editors. ***Spinal Cord Injury: A Guide To Care.*** New York University Medical Center, Health Care Center Room 1430, 530 First Ave., New York, NY 10016, 1980, 89 pages, $4.25.

Good, clear simple information. Good illustrations.

LEPROSY

+++++ Watson, Jean. ***Preventing Disability in Leprosy Patients.*** The Leprosy Mission, 50 Portland Pl., London, W1N 3DG, England, 1986, 116 pages, $1.50.

Excellent, simple, clear, well-illustrated.✓

A shorter version of this book (32 pages), entitled ***Essential Action to Minimise Disability in Leprosy Patients,*** is available at no cost.

++++ ***Leprosy: A Pack of Teaching Materials. (1984).*** OXFAM, 274 Bandbury Rd., Oxford, OX2 7DZ, England. Price £10 British pounds or US $15.00.✓ This excellent, highly-recommended collection includes:

1. ***Chemotherapy of Leprosy for Control Programmes.*** Technical Report Series 675, World Health Organization.
2. McDougall, A. Cohn. ***Questions and Answers On the implementation of Multiple Drug Therapy (MDT) for Leprosy.***
3. Bryceson, Anthony, and Pfaltzgraff, Roy. ***Leorosy.***
4. Browne, Stanley. ***The Diagnosis and Management of Early Leprosy.***✓
5. ***Better Care in Leprosy.*** Published by the Voluntary Health Association of India.
6. Brand, Paul. ***Insensitive Feet: A Practical Handbook on Foot Problems in Leprosy.***
7. Leiker, D.L., and McDougall, A.C. ***Technical Guide for Smear Examination for Leprosy by Direct Microscopy.***
8. Guinto, Ricardo; Abalos, Rodolfo; Celiona, Roland; and Fajardo, Tranquilino. ***An Atlas of Leprosy.***

++ ***A Guide to Leprosy for Field Staff.*** All Africa Leprosy and Rehabilitation Training Centre, P.O. Box 165, Addis Ababa, Ethiopia, 1977, 62 pages.

Rather 'academic' (like a school text book) but has some good Practical suggestions and information.

++++ Neville, P. Jane, editor. ***A Footwear Manual for Leprosy Control Programmes.*** All Africa Leprosy and Rehabilitation Training Centre, P.O. Box 165, Addis Ababa, Ethiopia, 1977, 118 pages.

Good, simple, well-illustrated, detailed instructions for many types of shoes, sandals, boots, and braces. ✓

Also available from the above address are 2 other excellent publications by the same author: ***A Simple Sandal for Insensitive Feet (1981, 24 pages), and A Guide to Health Education in Leprosy*** (1980, 20 pages).

++ Kelly, Ellen. ***Physical Therapy in Leprosy for Paramedicals-Levels I, II, and III.*** American Leprosy Missions, Inc., 1 Broadway, Elmwood Park, NJ 07407, USA, 1981, 235 pages, free.

Lots of complicated theory without much practical information relating to real persons with leprosy. But has some useful suggestions.

++ Jacyk, ***W K. Leprosy in Africans.*** German Leprosy Relief Association, Postffach 348, D-8700, Wurzburg 11, West Germany, 1983, 52 pages.

Excellent color photo guide for diagnosis.

++ Thangaraj, R. H. ***A Manual of Leprosy.*** The Leprosy Mission, CNI Bhavan, 16 Pandit Pant Marg, New Delhi 110 001, India. Third edition, 1983, 342 pages.

Well-balanced and complete, with good illustrations. Language fairly complex. ✓

+++ "PARTNERS-Magazine for paramedical workers in leprosy." Available in English, French, and Portuguese. For information, write The Leprosy Mission, 50 Portland Pl., London, WIN 3DG, England.

Excellent, up-to-date information and ideas for community work.

Note: The Leprosy Mission also has a list of 24 publications on leprosy available. Write to your local Leprosy Mission or to the above address for a price list.

American Leprosy Missions. 1 Broadway, Elmwood Park, NJ 07407. Publishes over 50 books and pamphlets on leprosy. Many are free.

+++ Color transparency sets are available from TALC, P.O. Box 49, St. Albans, Hertfordshire ALI 4AX, England. Slide sets on leprosy in children-for different skin colors: Africa and Asia. Also care of nerve, damaged limb. Send for price list.

+ Microfiche transparencies available from Royal Tropical Institute, Department of Publications, Mauritskade 63, 1092 AD Amsterdam, Netherlands, 84 pictures for $ 10.00. Hand viewer for $2.00.

BLINDNESS

++++ Fichtner, Dorothea. ***How To Raise a Blind Child: A Guide For Parents of Blind Children and Those Who Work With Blind Pre-school Children.*** Christoffel Blindenmission Press, Nibelungenstrasse 124, D-6140 Bensheim 4, West Germany. 1979, 64 pages. DM 5.50 plus Postage.

Excellent introduction for the family. Filled with excellent information as well as love and understanding. Good Photos.✓

+ Scott, Eileen; Jan, James; and Freeman, Roger. ***Can't your Child See?*** PRO-ED, 5341 Industrial Oaks Blvd., Austin, TX 78735, 1985, 248 pages.

Information often in the form of stories about different blind children. Warm and supportive, but oriented to developed urban society.

+++ Horton, J. Kirk ***Community-based Rehabilitation of the Rural Blind: A Training Guide for Field Workers.*** Division of Education and Rehabilitation, Helen Keller International, 15 West 16th St., New York, NY 10011, USA. 131 pages, $5.00.

Good information, well illustrated.✓

+++ Drouillard, Richard, and Raynor, Sherry. ***Move It*** (A Guide for helping visually handicapped children grow). 73 pages, and ***Get a Wiggle On*** (A guide for helping visually impaired children grow), 80 pages. AAHPERD Publication Sales, 1900 Association Dr., Reston, VA 22091, USA, 1977 and 1975.

Enjoyable booklets with many ideas, simply presented with cartoon pictures.

++ ***A Different Way of Seeing.*** A pamphlet published by the American Foundation for the Blind, 15 West 16th St., New York, NY 10011, USA.

++ Farrell, Kay Alicyn. ***Reach Out and Teach: Materials for Parents of Visually Handicapped and Multi-handicapped Young Children.*** American Foundation for the Blind, 15 West 16th St., New York, NY 10011, USA. 1) Parent Handbook, 1985, 272 pages, 2) Reachbook (a companion workbook), 1985, 176 pages, 3) Slide/tape presentations and teacher's manual also available.

DEAFNESS

+++ Texas Education Agency. ***Preferred Signs for Instructional Purposes and Supplement to Preferred Signs.*** 1701 N. Congress Ave., Austin, TX 78701, 1982 (12th printing), 505 pages, $6.00, supplement 119 pages, $2.00.

Good, very complete manual on sign language for the deaf-United States of America system. Comes with separate trainers' manual.✓

++ "National Association of the Deaf Catalog of Publications." National Association of the Deaf, 814 Thayer Ave., Silver Spring, MD 20910.

Lists of many resources-some much more helpful than others.

++ ***Sign and Say.*** Royal National Institute for the Deaf, 105 Dower St., London, WCIE 6AH.

+ Evans, Lionel. ***Total Communication: Structure and Strategy.*** Gallaudet College Press, Washington DC, 1982, 160 pages.

Written in elevated language. Suggested for persons interested in the history and philosophy of total communication.✓

++ Miller, Ralph R. Sr.***Sign Language Clowns: An Educational Coloring Book for Elementary and Pre-school Children.*** Dawn Sign Press, 2490 Channing Way #510. Berkeley, CA 94704, 1985, 32 pages.

Easy to use and enjoyable. Pages can be cut out and made into cards and posters.✓

+++ ***Modern Signs Press, Inc.*** P.O. Box 1181, Los Alamitos, CA 90720. Publishes materials (flash cards, books, videotapes) on a communication method called Sign Exact English, a sign system for learning how to read and write English. We have used signing cards for persons with no language skills (Kit A), and ***Signos Para El Inglés Exacto,*** a book for Spanish-speaking families of deaf children in schools using Sign Exact English. Send for free brochure.✓

+++ O'Rourke, Terrence J., Director. ***A Basic Course in Manual Communication.*** Communication Skills Program, The National Association of the Deaf, 814 Thayer Ave., Silver Spring, MD 10910, 1979, 161 pages.

Contains 737 illustrations of signs, finger spelling, and numbers. Useful to teach from. Good reading not required. Relatively inexpensive.✓

DEAFNESS, continued

+++ Riekehof, Lottie L. ***The Joy of Signing*** Gospel Publishing House, Springfield, MO 65802, 1978, 336 pages.

Good basic teaching book; clear drawings of signs, USA system. ✓

+++ Thorburn, Marigold. 'Small Talk: Communication for the Child with Speech and Hearing Problems'.

Adapted from the WHO manual, ***Training the Disabled in the Community.*** Caribbean Institute on Mental Retardation and Other Developmental Disabilities, 94c Old Hope Rd., Kingston 6, Jamaica, 1983, 63 pages.

Good introduction. For developing countries. ✓

+++ Larson, Heidi, editor. ***Speech and Hearing.*** A booklet about ways to prevent, identity, and rehabilitate speech and hearing impairments among children.

Rehabilitation International/UNICEF, Technical Support Program, Kathmandu, Nepal, 1983, 32 pages.

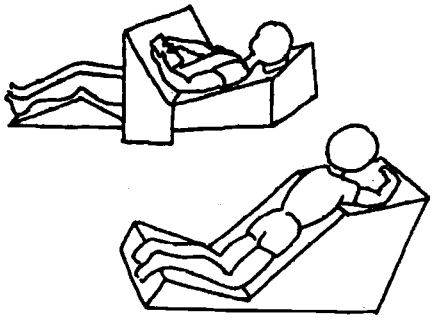
Good introduction, excellent drawings, very brief. For developing countries.✓

THERAPY, EXERCISES, AND POSITIONING

+++ Bergen, Adrienne Falk and Colangelo, Cheryl. ***Positioning the Client With Central Nervous System Deficits: The Wheelchair and Other Adapted Equipment.*** Valhalla Rehabilitation Publications, P.O. Box 195, Valhalla, NY 10595, 1985 (second edition), 237 pages, $29.95.

Detailed, in-depth discussion of adaptive seating to meet needs of individual children with cerebral palsy.

Excellent illustrations. Rather technical. Language fairly complex. ✓



+++ Jaeger and Hewift. 'Home Program Instruction Sheets for Infants and Young Children', and 'Range-of-Motion'.

University of Kentucky, Department of Physical Therapy, College of Allied Health Professions, 1980.

Excellent well-illustrated instruction sheets.✓

+ Leévy, Janine. ***The Baby Exercise Book: For the First Fifteen Months.*** Pantheon Books, 201 E. 50th St., New York, NY 10022, $6.95.

Exercises for non-disabled babies to encourage healthy development. Many also useful for disabled babies.

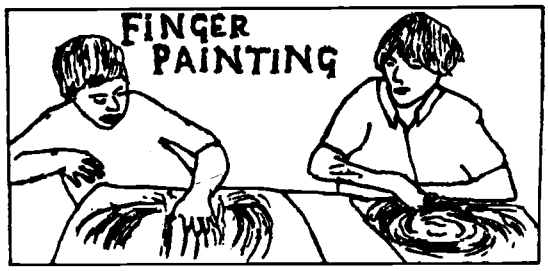
+++ Ward, Diane. ***Positioning the Handicapped Child For Function.*** Phoenix Press, Inc., P.O. Box 14-8337, Chicago, IL 60614, 1984, 137 pages.

Many simple ideas and designs for positioning children-mainly those with cerebral palsy.

CHILD DEVELOPMENT AND DEVELOPMENTAL DELAY

+++++ Miles, Christine. ***Special Education For Mentally Handicapped Pupils.*** Niraii Kitaben, 6 Empress Rd., Lahore 5, Frontier Province, Pakistan, 1984, 151 pages. Books sent to addresses in the USA can be ordered from the Hesperian Foundation for $6.00.

Excellent adaptation of special education to a developing community. Clearly written. A few good illustrations (could use more). Perhaps the best special education text for community programs. ✓



++ Cliff, Shirley; Gray, Jennifer; and Nymann, Carol ***Mothers Can Help: A Therapist's Guide for Formulating A Developmental Text for the Parents of Special Children.*** El Paso Rehabilitation Center, 2630 Richmond, El Paso, TX 79930, USA, 1981, 212 pages, $11.95.

Simple, basic information for step-by-step help with development of the retarded child.

+++ Click, Marilyn and Davis, Joan. ***Moving Right Along: Developmental Goals For Physically Disabled Children.*** EDCorp Publications, P.O. Box 17146, Mesa, AZ 85212, USA, 1985, 213 pages, $21.95.

A simple goal-and Problem-oriented step-by-step approach. Well illustrated.

++ Cunningham, Cliff and Sloper, Patricia. ***Helping Your Exceptional Baby: A Practical and Honest Approach to Raising a Mentally Handicapped Child.*** Pantheon Books, Random House, Inc., New York, NY, USA, 1980, 335 pages.

Good basic information, but some of the other books are better.

++ Frankel, Max; Happ, F. William; Smith, Maurice. ***Functional Teaching of the Mentally Retarded.*** Charles C Thomas Books, 301-327 East Lawrence Ave., Springfield, IL, USA, 1975, 265 pages.

Many good ideas, games, and teaching materials. Rather wordy and complex. Many illustrations. Somewhat boring. ✓

++ Hanson, Marci J. ***Teaching Your Down's Syndrome Infant: A Guide for Parents.*** PRO-ED, 5341 Industrial Oaks Blvd., Austin, TX 78735, 1986, 250 pages.

A very programmed, step-by-step approach.✓

++ ***Low Cost Teaching Aids for Special Education.*** Commonwealth Education Handbooks, Marlborough House, London SWI Y 5HX, England, 1982, 43 pages.

Some useful ideas.

BEHAVIOR TRAINING AND TOILET TRAINING

+++ Newson, Elizabeth and Hipgrave, Tony. ***Getting Through To Your Handicapped Child.*** Cambridge University Press, Pitt Building, Trumpington St., Cambridge, England, CB2 1RP, 1982, 134 pages. Also available from Cambridge University Press, 510 North Ave., New Rochelle, NY 10801. $7.95.
Good presentation of a behavioral approach to learning, but rather complicated. ✓

++ Kelly, Jeffrey. ***Solving Your Child's Behavior Problems.*** Little, Brown, and Company, Boston, MA, 1983, 201 pages.
Good presentation of the behavioral approach to learning.

++ Gordon, Thomas. ***Parent Effectiveness Training.*** New American Library, P.O. Box 999, Bergenfield, NJ 07621, USA, 1975, 334 pages, $7.95 + $1.50 postage and handling.
A variation of the behavioral approach to learning. Mainly for non-disabled children but ideas also work for the disabled.

++ Azrin, Nathan, Ph.D., and Foxx, Richard, Ph.D. ***Toilet Training In Less Than a Day.*** Pocket Books, 1230 Avenue of the Americas, New York, NY 10020, 1974, 189 pages, $2.95.
Good instructions for 'the fast method'; oriented to USA and Europe.

PLAYGROUNDS AND TOYS

++ ***An Instructional Playground For the Handicapped-Using Tires As Inexpensive Playground Equipment: Activity and Construction Manual.*** University of the State of New York, State Education Department, Division for Handicapped Children, Special Education Instructional Materials Center, 55 Elk St., Albany, NY 12234, USA, 50 pages.
Many good ideas for using old tires. ✓

++ Hogan, Paul. ***Playgrounds For Free: Utilization of Used and Surplus Materials in Playground Construction.*** The MIT Press, 28 Carleton St., Cambridge, MA, 1979, 252 pages, $10.95.
Many good ideas. Not especially for disabled children but much of the equipment can be used by them. Many of the play things are too big and complex to make in a small village. ✓

++ ***Adventure Playgrounds For Handicapped Children.*** Handicapped Adventure Playground Association, Fulham Palace, Bishops Ave., London SW6 6EA, England, 1978, 32 pages.
Good but rather elaborate playground ideas for all children.

++ ***Juguetes Que No Cuestan Nada.*** UNICEF. CONAFE, Mexico, 1983, 20 pages.
Very simple attractive ideas for toys made by children. Good illustrations. Spanish only.

++ Grantham-McGregor, Sally. ***Toys You Can Make For the Under Twos (Book 1),*** 19 pages, and ***Toys You Can Make For the Under Fours (Book 2),*** 20 pages. UNICEF Caribbean Area Office, British Overseas Development Agency, 1980.
Very simple, easy-to-make toys.

++ Coy, Kendrick. ***Multi-Sensory Educational Aids From Scrap.*** Charles C Thomas Books, 2600 South First St., Springfield, IL 62717 USA, 1980, 232 pages, $28.50.
Many good ideas.

+++ ***MIKKY: Visual Aids and Toys.*** Life Help Centre for the Handicapped. East Coast Rd., Palavakkam, Madras 600 041, India

++ McConkey, Roy and Jeffree, Dorothy. ***Making Toys for Handicapped Children, A Guide for Parents and Teachers.*** Prentice Hall Publishers, Englewood Cliff, NJ 07632, 1983, 200 pages.
Many good ideas.

+ Cratty, Bryant J. and Breen, James E. ***Educational Games For Physically Handicapped Children.*** Love Publishing Company, 1777 South Bellaire St., Denver, CO 80222, 1972, 91 pages, $4.95.
Many good ideas. Developed country orientation.

AWARENESS RAISING; POLITICS OF DISABILITY, REHABILITATION, AND MEDICINE

++++ Miles, Mike. ***Where There Is No Rehab Plan.*** Mental Health Center, Peshawar, Pakistan, N.W.F.P. Also available from The Hesperian Foundation, 63 pages, $3.50.
Good analysis of 'community-based rehabilitation' criticizing the WHO approach.

+++ Jones, Ron. ***The Acorn People.*** Bantam Books, Inc., 666 Fifth Ave., New York, NY 10103, 1976, 80 pages.
A good, very human story about disabled children and their need for freedom, adventure, and understanding.

+++ Davidson, Margaret. ***Louis Braille: The Boy Who Invented Books For the Blind.*** Scholastic Book Services, 730 Broadway, New York, NY 10003, 1971, 80 pages, $1.95.
Excellent story for children about the accomplishments of a disabled child. Good reading for CHILD-to-child. ✓

++ Melrose, Dianna. ***Bitter Pills-Medicines and the Third World Poor.*** OXFAM, 274 Banbury Rd., Oxford, OX2 7DZ, England, 1982, 277 pages.
Excellent discussion of how drug companies often exploit the people and endanger their health.

+++ Schoolboys of Barbiana. ***Letter to a Teacher.*** Vintage Trade Books, Random House, 201 E. 50th St., New York, NY 10022, 1970. 167 pages.
Not related to disability-unless poverty is a disability.
Excellent 'bottom-up' analysis of istitutionalized oppression of the poor

+++ CHILD-to-child Activity Sheets on many subjects, including disability (see list on p.427 and 428), are available from TALC, P.O. Box 49, St. Albans, Herts. AL1 4AX, England.
Excellent guides for activities with children to help other children. See Chapter 47. ✓

+++ Gudmundsson, Johann. ***Cooperatives of Disabled Persons: A Guide for Promotion and Organization.*** 1985, 181 pages. Committee for the Promotion of Aid to Cooperatives (COPAC), Via delle Terme di Caracalla, 00100 Rome, Italy.
Includes a directory of cooperatives for disabled persons in 32 countries.

AIDS, APPLIANCES, AND SPECIAL EQUIPMENT, INCLUDING WHEELCHAIRS

++ ***How To Make Basic Hospital Equipment,*** compiled by Roger England, Intermediate Technology Publications, Ltd., 9 King St., London, WC2E 8HN, England, 1979, 86 pages.

Simple tube metal wheelchairs and other designs from Africa. Well illustrated. Language fairly simple. ✓

+++ ***Asia-Pacific Disability Aids and Appliances Handbook.*** ACROD, P.O. Box 60, Curtin. A.C.T., 2605, Austalia, 1982, 84 pages.

A good collection of designs from many sources, each illustrated and with useful comments.✓

+++ ***UPKARAN: A Manual of Aids For the Multiply Handicapped.*** Spastics Society of India, Upper Colaba Rd., Opposite Afghan Church, Colaba, Bombay, 400-005 India, 106 pages.

Many excellent, mostly simple aids, well illustrated, in English and Hindi.✓

++ Robinault, Isabel, editor. ***Functional Aids for the Multiply Handicapped.*** Medical Department, Harper and Row, Publishers, Inc., 2350 Virginia Ave., Hagerstown, MD 21740, 1973, 233 pages. Lots of good ideas and designs. Some simple, many fairly complicated. Language fairly easy. Excellent illustrations.✓

++ Grainger, Stuart E. ***Making Aids For Disabled Living.*** B. T. Batsford Ltd., 4 Fitzhardinge St., London W1H OAH, England, 1981, 87 pages.

Some good ideas and designs. Most very polished. Includes good wheelchair tables.

++ Hutt, J.K. ***Rattan and Bamboo.*** Disabilities Study Unit, Wildhanger, Amberley, Arundel, W. Sussex BN8 9NR, England, 1979, 26 pages, £2.00.

Excellent designs for countries where people have skill working with rattan. ✓

+++ ***Low cost aids.*** AHRTAG, 85 Marylebone High St., London, W1M 3DE, England, 1982, 54 pages.

Very simple aids children can make themselves. Good drawings.✓

++ Caston, Don and Thompson, Joan. ***Low Cost Physiotherapy Aids,*** 1982 56 pages, and ***Low Cost Walking Aids,*** 1983, 22 pages, AHRTAG, (see above).

Very simple aids children can make themselves.

+++ 'Aids for Living', (Newsletter) AHRTAG, (see above). No cost. Many good ideas.✓

++ Caston, Don. ***Easy to Make Aids for Your Handicapped Child.*** Souvenir Press, 43 Great Russell St., London, WC 1 B 3PA, England.

Aids made of finished wood or plywood.

+++ ***More With Less: Aids for Disabled People for Daily Living.*** TOOL, Technical Development with Developing Countries. Entrepotdok 68A/69A, 1018 AD Amsterdam, The Netherlands.

Simply written, in both English and Spanish, with illustrations on every page. 1986. 90 pages.

+++ Dartnell, Chris, ***Simple Orthopaedic Aids.*** Leonard Cheshire Foundation International. 26-29 Maunsel St., London, SW1P 2QN, England, 1983, 44 pages.
Simple, low-cost braces and artificial limbs.✓
(For a list of books with designs of wheelchairs and special seating, see p.730 to 732.)

ARTIFICIAL LIMBS

++++ ***Simple Below-knee Prosthesis Manufacture, 1985, 80 pages, and Simple Above-knee Prosthesis Manufacture,*** 1986, 90 pages, Operation Handicap International, 18 rue de Gerland 69007, Lyon France (English and French).
Excellent, fairly simple method. See p. 764-765.

++ Anderson, Miles; Bray, John; and Hennessy, Charles. ***Manual of Above Knee Wood Socket Prosthetics.*** Charles C Thomas Books, 2600 South First St., Springfield, IL 62717, USA, 1980, 296 pages, $34.50.
Detailed instructions, but requires considerable skill and equipment. See p. 766.✓

++ Anderson, Miles; Bechtol, Charles; and Sollars, Raymond. ***Clinical Prosthetics for Physicians and Therapists.*** Charles C Thomas Books, (see above). 396 pages, $36.50.

A large, informative book on artificial arms and legs. Good section on training for use. Good step-by-step instructions for making wood sockets. Some difficult language and complicated theory.✓

++ Radcliffe, C.W. and Foort, J. ***The Patellar-Tendon-Bearing Below-Knee Prosthesis.*** Department of Engineering, University of California, Berkeley, and School of Medicine, University of California, San Francisco, CA, USA, 1961, 214 pages.
Rather complicated, step-by-step instructions for making modern resin prostheses. These limbs require many materials, but the basic method can be learned quickly through apprentice training, and the limbs need not be very costly to make. Village workers at Project PROJIMO use these methods.

SLIDE SETS (color transparencies) related to disabilitiesandrehabilitation available from the Hesperian Foundation, P.O. Box 1692, Palo Alto, CA 94302, USA. All sets include a written script.

Project PROJIMO, 160 slides, $56.00. A descriptive presentation of PROJIMO, a community rehabilitation program in rural Mexico, run by disabled villagers to help disabled children and their families become more self-reliant.

Helping Your Neighbor, and ***A Disabled Child Discovers New Life,*** 24 slides, $8.40. Skits by the PROJIMO team and village children to show villagers how the rehabilitation program started and how it works.

Measles Monster, 25 slides, $8.75. A 'street theater' presentation in Nicaragua to promote cooperation in the vaccination campaign.

Family Care of Disabled Children, 30 slides, $10.50. Very simple ways in which families can help disabled children do more, using only what is available in the home. Discusses a few basic principles.

CHILD-to-child Activities in Mexico, 65 slides, $22.75. Includes many other slides on activities for understanding disabled children and for testing seeing and hearing.

(Other sets are being prepared. Write the Hesperian Foundation.)

LIST OF SPECIAL OR DIFFICULT WORDS

This is a list in alphabetical order of words used in this book that you may not understand. The first time one of these words is used in the book, or in a chapter, it is written in italics so that you know you can look it up here, where we explain each word. Sometimes, we also refer you to a page of the book that explains the word more completely. If this list does not have a word you want explained, look in the INDEX. The word may be explained on a page that the INDEX refers you to. For example, 'arthrogryposis' is explained on p. 142.

A

Action nerves (motor nerves) Nerves that carry messages from the brain to parts of the body, telling muscles to move.

Acute Sudden and short-lived. An acute illness is one that starts suddenly and lasts a short time. It is the opposite of 'chronic'.

Adaptation Change or changes to better fit a specific child or local area. A seat may be adapted by the addition of straps and pads to better support the body.

Antibiotic A medicine that fights infections caused by bacteria. Penicillin and tetracycline are antibiotics. For discussion about antibiotics and their use, see ***Where There Is No Doctor.***

Arthritis Pain and inflammation in one or several joints of the body such as the knees, elbows, or hips.

Ataxia Difficulty with balance and with coordination. (See p. 100).

Atrophy A progressive wasting or weakening of the muscles that comes from a problem in the nerves. (Compare with 'dystrophy').

B

Behavior A person's way of doing things; pattern of actions. The way a child acts, or elates to others. (See Chapter 41).

Bladder A muscular bag in the belly in which urine collects before it leaves the body.

Bowel The part of the gut or intestine where solid waste (stool, shit) collects before it leaves the body.

Bowel movement Emptying of the bowel; shitting.

Butt Buttocks; backside; rear end; the part of the body on which a person sits.

C

Caliper British word for "brace." An aid which gives support to a weak or injured leg. (See Chapter 59).

Caster A wheel that is mounted so that it turns from side to side to go around corners The small wheels of a wheelchair are usually made with casters.

Chronic Long-term or frequently returning. A chronic disease is one that lasts a long time. Compare with 'acute'.

Circulation The flow of blood through the blood vessels (veins and arteries). Good circulation is necessary for healthy body parts.

Clog A wooden sandal or shoe, often used with a brace.

Contracture Reduced range of motion in a joint, often due to muscle shortening (See Chapter 8).

Cord A simple name for 'tendon', a part of the body that connects muscle to bone. For example, the 'heel cord' or 'Achilles Tendon' joins the calf muscle to the heel. (***Note***: The 'spinal cord' is not a tendon. It is made of nerves. (See p. 37).

D

Diaper (nappy) A cloth to soak up urine, usually worn by a child.

Diplegia Paraplegia in which the upper part of the body is also slightly affected. (See p. 100).

Disability A long-lasting or permanent defect or problem that in some way makes it more difficult for a person to do certain things than for a 'non-disabled' person. A disability can be;

mild: Causes some inconvenience but the person can learn to do everything he or she needs to.

moderate: Person needs to make adaptations to be independent in self-care and other activities.

severe: Person will always need help for some or all self-care and other activities.

Dislocation Damage to a joint; the bone ends have slipped outof their normal position. Dislocation can be from birth, from and accident, or from weakness and 'muscle imbalance'.

Dystrophy A progressive muscle weakness that comes from a problem in the muscles themselves. Compare with 'atrophy'.

E

Evaluation Observations and study to find out how well something is working and where the problems are.

F

Functional Useful; serving some purpose for day-to day life.Exercise or therapy is functional when it is done as part of some useful activity.

Flacid Lacking firmness; soft.

G

Gene A hereditary unit; something that controls or acts in the passing down of features from parent to child.

H

Hemiplegia Paralysis or loss of movement in the muscles of the arm and leg on one side of the body only.

Hereditary Familial a feature that passes from parent to child when the baby is first made (conceived). If a disease is hereditary, there is a factor or characteristic in the father and/ or mother which is passed on to their children, and then their children's children. Inherited.

Hygiene Actions or practices of personal cleanliness that protect health.

I

Infantile Of infants (babies) or young children

Infection A sickness caused by germs (bacteria, virus, worms, or other small living things). Some infections affect part of the body only, others affect all of it.

Inherited (same as Hereditary).

J

Joint capsule The tough covering around a joint.

Juvenile Of children.

L

Lathyrism Severe paralysis of the lower limbs (see chapter 34), caused by consumption of Khesari dal.

Ligament Tough strips or bands inside the body that hold joints and bones together. Ligaments join bones with other bones, while tendons or cords join bones with muscles.

Limb An arm or leg.

M

Mental Having to do with the mind or intelligence. A child who is mentally handicapped or retarded does not learn as quickly as other children.

Multiple disability Several disabilities, often both physical and mental, in the same child. (See p. 345).

Muscles Meaty parts of the body that pull or 'contract' to make the body and limbs move.

N

Nappy (diaper) A cloth to soak up urine, worn by a child who does not have bladder control

Nerve A thin line along which messages travel in the body. Nerves are the 'messengers' of the body. Some nerves let us feel things, and tell us when something hurts. Other nerves let us move parts of the body when we want to. (See p. 37).

O

Occupational Having to do with work or function. And occupational therapist is a person who helps figure out how a disabled person can do things better.

Orthopedic Aids, procedures, or surgery to help correct a physical deformity or disability.

Orthotist A brace maker.

P

Paralysis Muscle weakness; decrease or loss of ability to move part or all of the body.

Paraplegia Paralysis or loss of movement in the muscles of both legs (sometimes with slight involvement elsewhere) caused by disease or injury to the spinal cord.

Physical Having to do with the body and how it works, as distinct from 'mental', which has to do with the mind.

Physical therapist, physiotherapist A person who designs and teaches exercises and activities for physically disabled persons.

Positioning Helping a person's body stay in healthy or helpful positions-through special seating, padding, supports, or in other ways.

Procedure Some kind of medical, surgical, or technical action. For example, casting, strapping, and surgery are 3 procedures for correcting a club foot.

Progressive A progressive illness or disability is one that steadily gets worse and worse. For example, muscular dystrophy.

Prosthesis An artificial limb or other part of the body-for example, a wooden leg. 'Prosthetics' is the art of making prostheses.

Q

Quadriplegia (tetraplegia) Paralysis or loss of movement in the muscles of both arms and legs caused by disease or injury to the spinal cord, in the neck.

R

Rehabilitation The art of helping a person learn to live as best she can and do as much as possible for herself, given her limitations or disability.

Retarded Slow to develop. A mentally retarded child does not learn as quickly or remember as well as other children.

S

Sensory nerves Nerves that bring messages from parts of the body to the brain about what the body sees, hears, smells, and feels.

Social Having to do with the actions, values, decisions, and relationships within groups of people.

Spasticity Uncontrolled tightening or pulling of muscles that make it difficult for a person to control her movements. A muscle or a child with spasticity is said to be 'spastic'. Spasticity often occurs with brain damage, cerebral palsy, and spinal cord injury.

Spinal Having to do with the spine or backbone.

Spinal cord The main 'trunk line' of nerves running down the backbone. It provides communication (for movements and feeling) between the brain and all parts of the body. (See p. 203).

Spine Backbone; spinal column; the chain of bones, called vertebrae, that runs down the back.

Stimulation Sounds, sights, activities, toys, smells, touch, and anything else that makes a child take interest in things and develop the use of his body and senses. 'Early stimulation' refers to activities that help a baby develop his first responses and skills. (See p. 371).

Stool Shit; body waste that is usually solid; also known as bowel movement or feces.

T

Tendon A strong rope-like structure in the body that connects muscles to bones. In this book we mostly call tendons 'cords'.

Tetraplegia (see quadriplegia).

Therapy Treatment; planned exercise and activity for a person's rehabilitation. See 'physical therapy' and 'occupational therapy'.

Toxic Poisonous.

Transfer Moving from (or to) a wheelchair to a bed, chair, cot, car seat, toilet, or floor.

Trunk The body, not including the head, neck, arms, and legs.

U

Urine Liquid body waste, also known as "pee," or "piss."

V

Vaccination Immunization; to give certain medicines (vaccines) by injection or mouth to protect against infectious diseases such as polio and measles.

Velcro A strong, fuzzy plastic tape that sticks to itself. (The surface of one piece of the tape has little plastic hooks that catch onto the curly hairs on the other piece of the tape). Useful to use instead of buttons, buckles, or laces on clothes, braces and shoes—especially for children with poor hand control. (See p. 409-410).

Virus Germs smaller than bacteria, that cause some infectious (easily spread) diseases. Most viruses are not killed by antibiotics.

W

Weight-bearing Supporting the weight of the body on a particular joint or limb. For example, weight-bearing on the knee is possible if the strength of the thigh muscle is good, but not if it is poor.

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LIST OF CHILD GUIDANCE CENTRES IN INDIA

ANDHRA PRADESH

1. Child Guidance Clinic
   Department of Child Psychiatry
   Niloufer Hospital
   Red Hills, Hyderabad
   Andhra Pradesh.

2. Child Guidance Clinic
   Rani Chandramani Devi
   Children's Hospital
   Rehabilitation Centre for
   Handicapped Children
   Visakhapatanam - 530 023.

3. Child Guidance Clinic
   18-11-578,
   Indian Red Cross Society Building
   Gaddiannaum
   Hyderabad - 500 669
   Andhra Pradesh.

BIHAR

4. Child Guidance Clinic
   Central Institute of Psychiatry
   Kanke
   Ranchi - 834 006
   Bihar.

5. Child Guidance Clinic
   Department of Paediatrics
   Patna Medical College
   Patna - 800 004
   Bihar.

CHANDIGARH

6. Child Guidance Clinic
   Department of Psychiatry
   PG Institute of Medical
   Education and Research,
   Chandigarh.

DELHI

7. Child Guidance Clinic
   Paediatrics Department
   Lok Nayak J.P.N. Hospital
   New Delhi.

8. Child Guidance Centre
   Department of Social Work
   University of Delhi
   3, University Road
   Delhi - 110 007.

9. Child Guidance Clinic
   Department of Psychiatry
   Dr. Ram Manohar Lohia Hospital
   New Delhi.

10. Child Guidance Clinic
    Department of Paediatrics
    Maulana Azad Medical College
    Associate LNJP Hospital
    New Delhi.

11. Child Guidance Clinic
    Rajkumari Amrit Kaur College
    of Nursing
    Lajpat Nagar
    New Delhi.

12. Child Guidance Clinic
    Kalawati Saran Children's Hospital
    Lady Hardinge Road
    New Delhi.

13. Child Guidance Clinic
    Rehabilitation Centre for
    Mentally Retarded
    Mandir Marg
    NDMC Health Complex
    New Delhi.

14. Child Guidance Clinic
    Department of Psychiatry OPD
    IInd Floor, AIIMS,
    Ansari Nagar
    New Delhi - 110 029.

15. Child Guidance School Society
    Shantideep
    B-66, Moti Nagar
    New Delhi - 110 015.

16. Child Guidance Centre
    Dr. Zakir Husain Memorial Society
    Jamia Millia Islamia
    Jamia Nagar
    New Delhi 110 025.

GUJARAT

17. Child Guidance Centre
c/o Indian Council of Social Work
M.S. University of Baroda
Baroda
Gujarat.

18. Mental Health Clinic
Department of Psychiatry
B.J. Medical College and
New Civil Hospital
Ahmedabad
Gujarat.

19. Government Mental Hygiene and
Psychiatric Child Guidance Clinic
Near Sanyas Ashram
Ellis Bridge
Ahmedabad - 390 006
Gujarat.

20. Child Guidance Clinic
Department of Psychiatry
Seth K.M. School of P.G. Medicine
and Research
V. S. Hospital (General)
Ahmedabad
Gujarat.

21. Child Guidance Clinic
Department of Psychiarty
Medical College and SSG. Hospital
Baroda
Gujarat.

22. Bal Marg Darshan Kendra
Alembic Vidyalaya
Alembic Colony
Baroda - 390 005
Gujarat.

23. Child Guidance Clinic
B.M. Institute of Mental Health
Near Nehru Bridge
Navarangpura
Ahmedabad - 380 009
Gujarat.

24. Child Guidance Clinic
DPCL School
Petro-chemical
Township
Baroda.

25. The Incharge
Navrachana Child Guidance Centre
Navrachna Ms Secondary School
Jyoti Colony, Sama Road
Baroda - 390 008
Gujarat.

26. Child Guidance Centre
Family Welfare & Planning Centre
c/o Bhai Lal Amin General Hospital
Gorwa
Baroda
Gujarat.

27. Child Guidance Centre
K G Patel Children's Hospital
Karoli Bang Jalaram Marg
Baroda - 390 018
Gujarat.

28. Ratna Bilwani
Child Guidance Centre
Ground Floor Borsali Apartment
Near Sabar Hotel, Ahanpur
Ahmedabad - 380 001
Gujarat.

KARNATAKA

29. Child Guidance Clinic
Department of Paediatrics
Vani Vila Children's Hospital
Bangalore - 560 002
Karnataka.

30. Child Psychiatry Unit
National Institute of Mental Health
and Neuro Sciences
Post Bag. No. 2979
Bangalore 560 029
Karnataka.

31. Child Guidance Clinic
Children's Hospital
Combined Hospitals
Medical College,
Bangalore
Karnataka.

32. Child Guidance Clinic
Dharwar Mental Hospital
Dharwar - 580 008
Karnataka.

33. Child Guidance Clinic
Department of Psychiatry
C. G. Hospital
Devangere - 577 004
Karnataka.

34. Child Guidance Clinic
Family Service Agency
Roshmi Nilaya
Mangalore - 575 002

35. Child Guidance Clinic
Kasturba Medical College and Hospital
Manipal, Karnataka.

MADHYA PRADESH

36. Child Guidance Clinic
B.S. Centre of Neuro-Psychology
and Counselling
University of Saugar
Saugar - 470 003
Madhya Pradesh.

37. Incharge
Child Guidance Clinic
Paediatric Department
M.Y. Hospital and MGM Medical
College
Indore, Madhya Pradesh.

MAHARASHTRA

38. Child Guidance Clinic
Psychiatric Wing
Armed Forces Medical College
Pune, Maharashtra.

39. Child Guidance Clinic
Seva Niketan
Sir J. J. Road, Byculla
Bombay
Maharashtra.

40. Kamayani Child Guidance Clinic
1187/641, Shivaji Nagar
Pune
Maharashtra.

41. Child Guidance Clinic
Department of Paediatrics
Medical College
Aurangabad 431 001
Maharashtra.

42. Child Guidance Clinic
T.N.M. College
B.Y.L. Nair Charitable Hospital
Souter Street, Opposite Zoola Maidan
Bombay
Maharashtra.

43. Child Guidance Clinic
Department of Psychiatric
K.E.M. Hospital, Parel
Bombay - 400 012
Maharashtra.

44. Child Guidance Clinic
St. Caterine of Science
School Welfare Society for
Destitute Children
Adjoining St. Mary Convent
17 C Bandra, Bombay - 400 050
Maharashtra.

45. Child Guidance Clinic
Bahi Jerbai Wadia Hospital for Children
Acharya Donda Marg, Parel
Bombay - 400 010
Maharashtra.

46. Child Guidance Clinic
Gujarat Research Society
Subodh Mehta Medical Centre
"TRAILOKYA"
16th Road, Khar (South Avenue)
Bombay - 400 052
Maharashtra.

47. Child Guidance Clinic
Institute of Child Health
J.J. Group of Government Hospital
Byculla, Bombay - 400 008
Maharashtra.

48. Child Guidance Clinic
Department of Psychiatry
LTMM & LTMG Hospital
Sion - 400 022
Bombay, Maharashtra.

49. Child Guidance Clinic
Nagpada Neighbourhood House
Sophia Zuber Road
Opp. Nagpada Police Station
Byculla
Bombay - 400 005
Maharashtra.

50. Child Guidance Clinic
Department of Psychiatry
Bombay Hospital
Marine Lines
Bombay, Maharashtra.

51. Child Guidance Clinic
Department of Psychiatry
Bhabha Atomic Research Centre
Hospital Deonar
Anushakti Nagar
Bombay - 400 094
Maharashtra.

52. Child Guidance Clinic
Observation Home
Old Jail Road, Umarkhedi
Bombay - 400 009
Maharashtra.

53. Maharashtra State Women's Council
Child Guidance Clinic
Powvela Building
Opp. Excelsior Cinema
10, Raveline Street, Fort
Bombay - 400 001
Maharashtra.

54. C V Shah Child Guidance Clinic
Shri Manav Seva Sangh
255-57 Sion (West) Sangh
Bombay - 400 022,
Maharashtra.

55. Child Guidance Clinic
Society for the Protection of
Children in Western India
Byranjee Jeejeebhoy Home
for Children
Sharaddanand Road
Kings Circle, Matunga
Bombay - 400 019
Maharashtra.

56. Pedder Poly Clinic
Makani Manor
16G, Deshmukh Marg
Bombay - 400 026
Maharashtra.

57. Jeevan Jyoti Mandal
Child Guidance Clinic
Tarate Colony, Karve Road
Pune - 411 004

58. Child Guidance Clinic
District Probation and
After Care Association
Near Observatory
1162/6, Shivaji Nagar
Pune - 411 005
Maharashtra.

59. Child Guidance Clinic
Secondary Teachers
Training College
Dhobi Talao
Bombay - 400 002
Maharashtra.

60. Child Guidance Clinic
Apostolic Camel High School
Baudia,
Bombay - 400 050
Maharashtra.

61. Child Guidance Clinic
Chembur Comprehensive
College of Education
Chembur Nagar
Bombay - 400 071
Maharashtra.

62. Child Guidance Clinic
Indian Red Cross Society
Poona District Branch
11, MG Road
Pune,
Maharashtra.

63. Child Guidance Clinic
Symobiosis Premises
Sonapati Bapat Road
Pune - 411 004
Maharashtra.

64. Guidance & Counselling Centre
Prognya Manas Samshodhika
Jnana Prabodhini
510, Sadashiv Peth
Pune - 411 030
Maharashtra.

ORISSA

65. Child Guidance Clinic
Ispat General Hospital
Rourkela
Orissa.

PUNJAB

66. Child Guidance Clinic
Govt. Mental Hospital
Amritsar,
Punjab.

RAJASTHAN

67. Child Guidance Clinic
Psychiatry Centre
Jaipur
Rajasthan.

TAMILNADU

68. Child Guidance Clinic
Government Mental Hospital
Kilpauk
Madras
Tamil Nadu.

69. Child Guidance Clinic
Department of Paediatrics
Government Stanley Hospital
Madras
Tamil Nadu.

70. Child Guidance Clinic
Anbagam
(Institute for the Mentally Handicapped Children)
Race Course Road
Madurai- 625 002
Tamil Nadu.

71. Child Guidance Clinic
Madras Institute to Rehabilitate the Retarded
802, RV Nagar
Anna Nagar
Madras 800 102

72. Child Guidance Clinic
Opportunity School Bala Ralni Nilayam
5, Ritherdon Road
Madras - 800 007

UTTAR PRADESH

73. Child Guidance Clinic
Jail Department
Agra
Uttar Pradesh.

74. Child Guidance Clinic
Department of Paediatrics
Aligarh Medical College, Aligarh
Uttar Pradesh.

75. Child Guidance Clinic
G.C.M. Vidyapeeth
Kashi Vidyapeeth
Varanasi
Uttar Pradesh.

76. Child Guidance Clinic
Manovigyan Shala
Allahabad
Uttar Pradesh.

77. Child and Adolescent Unit
Department of Psychiatry
K.G.'s Medical College
Lucknow
Uttar Pradesh - 226 003.

78. Child Guidance Clinic
Department of Paediatrics
GSVM Medical College
Kanpur
Uttar Pradesh.

WEST BENGAL

79. The Project Director
Vikas Kendra
PO & Village Atghara
Via - Kolasur
Dt. 24 Parganas (North)
Calcutta.

80. Child Guidance Clinic
Indian Institute of Social Welfare and Business Management
College Square West
Calcutta.

81. Medu Social Worker
Foundation of Economic of Rural Youth
6, Raja Basanta Roy Road
Calcutta - 700 026
West Bengal.

NOTE

LIST OF IMPORTANT ORGANISATIONS

ACTION OF DISABILITY &
DEVELOPMENT INDIA (ADD)
105 B, Wellington Park
8 & 9 Wellington Street
Bangalore - 560 025
Karnataka

ALI YAVAR JUNG RASHTRIYA SHRAVAN
VIKLANG SANSTHAN (AYJNIHH)
Kishanchand Marg
Bandra Revlameshan, Bandra
Bombay - 400 050
Maharashtra

ALL INDIA INSTITUTE OF PHYSICAL
MEDICINE AND REHABILITATION
Haji Ali Park
Clerk Road, Mahalaxmi
Bombay - 400 034
Maharashtra

ALL INDIA INSTITUTE OF
SPEECH AND HEARING
Manasgangotri
Mysore - 570 006
Karnataka

AMAR JYOTI CHARITABLE TRUST
N-192, Greater Kailash-I
New Delhi - 110 048

AMAR JYOTI RESEARCH AND
REHABILITATION CENTRE
Karkar dooma
Vikas Marg,
New Delhi - 110 092

ANDH MAHA VIDYALAYA
Panch Kuian Marg
New Delhi - 110 001

ANDH MAHILA SABHA ISWARI PRASAD
Dattatracya Orthopaedic Centre
3 Adyar Bridge Road
Madras - 600 028
Tamil Nadu

ASSOCIATION OF THE
PHYSICALLY HANDICAPPED
II Henner Road,
Lingarajapuram
Bangalore - 560 001

BALA VIHAR TRAINING SCHOOL
Halls Road, Kilpauk
Madras - 600 010
Tamil Nadu

BALA VIKAS INSTITUTE
Gandhi Institute
Opp. Hindustan Latex
Peroorkada
Trivandrum - 695 005, Kerala

BALWANT RAY MEHTA VIDYA BHAWAN
Masjid Moth
Greater Kailash - II
New Delhi - 110 048

BURNS SOCIETY OF INDIA
103, Vijay Apartments
Bulabhai Desai Road
Bombay - 400 036

CENTRE FOR THE SPECIAL EDUCATION
Opp. Afghan Church
Upper Colaba Road, Colaba
Bombay - 400 005, Maharashtra

CENTRE FOR SPECIAL EDUCATION
c/o N.V. Gadgil School
No.5, Near Dakshin Mukhi Maruti,
Shaniwar Peth
Pune - 411 030
Maharashtra

CENTRE FOR SPECIAL EDUCATION
Thakkar Bapa Vidyalaya Campus,
36 Venkatanarayana Road
T Nagar, Madras - 600 017
Tamil Nadu
CHETNA,
Sector 'C'
Aliganj Housing Scheme
Lucknow - 226 020, Uttar Pradesh

CHETNA INSTITUTE FOR THE
MENTALLY HANDICAPPED
Lakshmi Vihar
Bhubaneshwar - 751 005
Orissa

CHILD DEVELOPMENT & RESEARCH CENTRE
AD-80 , 5th Avenue
Anna Nagar
Madras - 600 040, Tamil Nadu

CHILD IN NEED INSTITUTE
Vill. Daulatpur, P.O. Amagachi
Via: Joka
Distt. 24 Pargana (S)
West Bengal - 743 512

CHILDREN'S ORTHOPAEDIC HOSPITAL
Haji Ali Park
Clerk Road, Mahalaxmi
Bombay - 400 034
Maharashtra

CHRISTIAN MEDICAL COLLEGE
Dept. of Physical Medicine & Rehabilitation
Vellore
Tamil Nadu

DEEPSHIKA
70, Circular Road
Opp. Women's College
Ranchi, Bihar

DON BOSCO PREM NIVAS
Mangalagiri - 522 503
Guntur Distt.
Andhra Pradesh

EDUCATION & TRAINING INSTITUTE FOR MENTALLY RETARDED CHILD
29/24 Nandanvan Society
Race Course Road
Athwa Lines
Surat
Gujarat

GANDHI MEMORIAL LEPROSY FOUNDATION
Hindinagar, Wardha - 442 103
Maharashtra

GANDHI RURAL REHABILITATION CENTRE
Alampoondy, Gingee Taluk
South Arcot District
Tamil Nadu - 604 151

GOVT. HOME FOR THE CRIPPLED CHILDREN
Near Water Works
P.O. Harsool
Aurangabad - 431 001
Maharashtra

HELEN KELLER INSTITUTE FOR THE DEAF AND DEAF-BLIND
Municipal Secondary School
(South Wing)
N.M. Joshi Marg,
Near Sandhurst Bridge,
Byculla (W), Bombay - 400 011
Maharashtra

HANDICAP INTERNATIONAL
38 Cross Third, Colas Nagar
Pondicherry - 605 001

HOME FOR CRIPPLED CHILDREN
Bhaktinakar Station Road
Rajkot
Gujarat

HOME FOR CRIPPLED CHILDREN
Pensionpura,
Baroda
Gujarat

INSTITUTE FOR THE VISUALLY HANDICAPPED
P.O. Bimangarh, Narisingarh
Agargatala - 799 001
Tripura

INSTITUTE FOR THE PHYSICALLY HANDICAPPED
4, Vishnu Digamber Marg
New Delhi - 110 002

INSTITUTE OF SPEECH AND HEARING
Hennur Road
Bangalore 560 084
Karnataka

INTERNATIONAL BONE & JOINT TUBERCULOSIS CLUB
147, Periyar E.V.R. Road
Madras - 600 010
Tamil Nadu

JAN MADHYAM
C-1, Chirag Enclave
New Delhi - 110 048

JALPAIGURI WELFARE ORGANISATION
Club Road
PO & Dt. Jalpaiguri 735
101 West Bengal, India

JANAPADA SEVA TRUST
Karuna Griha
Melkote, Karnataka

KARNATAKA WELFARE ASSOCIATION
FOR THE BLIND
No. 69, S. C. Road
Seshadripuram
Nehru Nagar, Bangalore
Karnataka

LIFE HELP FOR THE HANDICAPPED
Madras Mahablipuram Road
Tirruvanmayur (Besant Nagar)
Madras - 600 050, Tamil Nadu

LIGHTHOUSE FOR THE BLIND
174, S. P. Mukherjee Road,
Calcutta - 700 026
West Bengal

MAHAROGI SEVA SAMITI
Anandwan
Via - Warora
Distt. Chandrapur - 442 914
Maharashtra

MON VIKAS KENDRA
Vikashpur, Kahilipara
Guwahati - 781 019
Assam

MUSCULAR DYSTROPHY SOCIETY
Institute of Physical Medicine
and Rehabilitation
Worly Seface
Bombay

NATIONAL ASSOCIATION FOR THE BLIND
Gujarat State Branch
c/o Blind Men's Association
Vastrapur, Ahmedabad
Gujarat

NATIONAL ASSOCIATION FOR THE BLIND
Kerala State Branch
Jagathi, Trivandrum - 695 014
Kerala

NATIONAL ASSOCIATION FOR THE BLIND
Karnataka State Branch
996 Hall II Stage
Indiranagar, Bangalore
Karnataka

NATIONAL ASSOCIATION FOR THE BLIND
Andhra Pradesh State Branch
C.G. Shroff Memorial Hospital
3-4-801, Barkatpura
Hyderabad
Andhra Pradesh

NATIONAL INSTITUTE FOR THE
MENTALLY HANDICAPPED
Manovikas Nagar
Bhovanpalli
Secunderabad - 500 011
Andhra Pradesh

NATIONAL INSTITUTE OF
MENTAL HEALTH AND
NEURO SCIENCES (NIMHANS)
Bangalore - 560 029
Karnataka

NATIONAL INSTITUTE OF NUTRITION
Indian Council of Medical Research
Hyderabad - 500 007
Andhra Pradesh

NATIONAL CENTRE FOR THE BLIND
(Model School for the Blind Children)
Department of Social Welfare
Government of India, Rajpur Road
Dehradun, Uttar Pradesh

NATIONAL INSTITUTE FOR THE
ORTHOPAEDICALLY HANDICAPPED
B.T. Road, Bonhooghly
Calcutta 700 090
West Bengal

NATIONAL INSTITUTE FOR THE
VISUALLY HANDICAPPED
116, Rajpur Road
Dehradun - 248 001
Uttar Pradesh.

NATIONAL CENTRE FOR
CEREBRAL PALSY
K. C. Marg
Bandra Reclamation
Bombay - 400 050
Maharashtra

NATIONAL JOB DEVELOPMENT CENTRE
The Spastic Society of India
Sion-Trombay Road, Chembur
Bombay - 400 071, Maharashtra

NAVJYOTI TRUST
A - 916, Poonamali High Road
Madras - 600 084, Tamil Nadu

NIMH REGIONAL TRAINING CENTRE (W)
C/o AYJNIHH, K.C. Marg
Bandra Reclamation, Bandra (W)
Bombay - 400 050, Maharashtra

NIMH REGIONAL TRAINING CENTRE (N)
Kasturba Niketan
Lajpat Nagar - II
New Delhi - 110 024

NASEOH (National Society for Equal
Opportunities for the Handicapped)
No. 11, Raj Bhavan Road
Bangalore - 560 001

NIRMALA SADAN
Muwattupuzha
Emakulam Distt.
Kerala 686 661

ORTHOPEADICLALY HANDICAPPED
CHILDREN HOME
Old Wood Art Training Hostel
Clerk Colony, Pardeshipura
Indore

PRATIBANDHI KALYAN KENDRA
Abinash Mukherjee Road
Post Office & Distt. Hooghly
West Bengal - 712 103

PREM ASHRAM MENTALLY RETARDED
CHILD SCHOOL
(Residential)
Una P.O.
Himachal Pradesh

PROJECT PRACHAR
Mar Geevarghese Dionysius Memorial Hospital
Davagiri, P.O.
Kangazha, Kottayam Distt.
Kerala - 686 555

RAHMANIYA SCHOOL
FOR HANDICAPPED
P.O. Medical College
Calicut - 673 008, Kerala

RAYALASEEMA SEVA SAMITHI
9, Old Huzur Office Bldgs,
Tirupati - 517 501

RED CROSS HOME FOR HANDICAPPED
Udhollah
Jammu

REHABILITATION CENTRE
FOR CHILDREN
59, Motilal Gupta Road
Barisha, Dehala (Sakher Bazar)
Calcutta - 700 008
West Bengal

REHABILITATION CENTRE
FOR MENTALLY HANDICAPPED
CHILDREN
6-3-1247, Sishugraham
Rajbhavan Road
Beside Lake-view Guest House
Hyderabad
Andhra Pradesh

RURAL ACTIVITIES COMMITTEE
National Association for the Blind
Haryana State Branch
1-C/90, NIT Faridabad
Haryana

SAMADHAN
J-32, South Extension Part I
New Delhi - 110 049

SCHIEFFLIN LEPROSY RESEARCH
AND TRAINING CENTRE
Karigiri
North Arcot District - 632 106

SCHIZOPHRENIA RESEARCH
FOUNDATION (SCARF)
C - 46, 13th Street, Anna Nagar
Madras - 600 102
Tamil Nadu

SCHOOL FOR DEAF AND
DUMB CHILDREN
Door No:6-3-33-335,
Dwarakapuri Colony, Punjagutta
Hyderabad - 500 004
Andhra Pradesh

SEVA-IN-ACTION
1486, 40th Cross
18th Main, 4th T-Block
Jaya Nagar, Bangalore - 560 041
Karnataka

SISHU SAROTHI
Spastic Society of Assam
Centre for Special Education
K.K. Bhatta Road, Chenikuthi
Guwahati - 781 001
Assam

SOCIETY FOR REHABILITATION
OF SPASTICS
Aizawl
Mizoram - 796 001

SOCIETY FOR THE REHABILITATION
OF CRIPLED CHILDREN
Children's Orthopaedic Hospital
Haji Ali Park, Clerk Road
Mahalaxmi
Bombay - 400 022
Maharashtra

SOCIETY OF EDUCATION FOR
THE CRIPPLED
Agrapada Municipal School Bldg.,
Motlibai Street
Bombay - 400 011
Maharashtra

SPASTIC SOCIETY OF EASTERN INDIA
P-35/1
Taratalla Road
Calcutta - 88.
West Bengal

SHRI RAMANA MAHARASHI ACADEMY
FOR THE BLIND
Sarakki, 3rd Phase
(Near Raji Guda)
J.P. Nagar, Bangalore - 560 078
Karnataka

ST. STEPHEN HOSPITAL
Dept. of Orthopaedics
Tis Hazari
Delhi - 110 054

THAKUR HARI PRASAD INSTITUTE OF
REHABILITATION FOR THE MENTALLY
HANDICAPPED
'Sishuniketan', Vivekanand Nagar
Dilsukhnagar, Hyderabad - 500 060
Andhra Pradesh

THE OCCUPATIONAL THERAPY
HOME FOR CHILDREN
109, Press Road
New Delhi - 110 002

THE SPASTICS SOCIETY OF INDIA
Nargis Dutt Bhavan
Kishanchand Marg
Bandra Reclamation, Bandra
Bombay - 400 050, Maharashtra

THE SPASTICS SOCIETY
OF NORTHERN INDIA (Delhi Branch)
Balbir Saxena Marg
Near General Raj's School
Opp. Gulmohar Park
Hauz Khas
New Delhi - 110 016.

THE SPASTIC SOCIETY OF TAMIL NADU
Opp. ITTI, Taramani Road
Madras - 600 113
Tamil Nadu

THE CHURCHES OF SOUTH INDIA
COUNCIL FOR CHILDCARE
50, Lavelle Road
Bangalore - 560 001

THE NATIONAL ASSOCIATION
FOR THE BLIND
Deptt. of Education
Rustam Alpaiwalla Complex
124-127 Cotton Depot
Cotton Green, Bombay - 400 033
Maharahstra

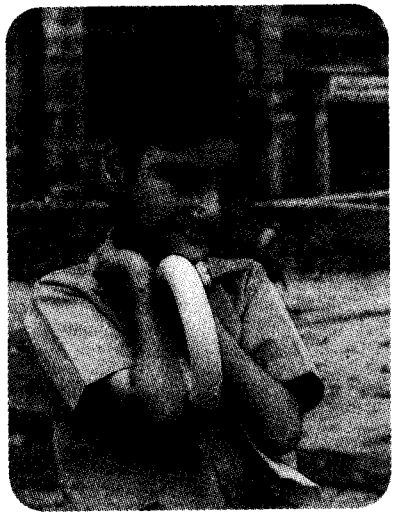
THE POONA SCHOOL AND HOME
FOR THE BLIND
14/17, Koregaon Park
Dr. Machave Road,
Pune - 411 001
Maharashtra

UJJWAL
5 Birbal Road
Jangpura Extension
New Delhi - 110 014

V.R. RUIA MOK BADHIR VIDYALAYA
Tilak College of Educational Compound
Behind S.P. College,
Tilak Road
Pune - 411 030
Maharashtra

VIKLANG KENDRA
Bhardwaj Ashram
13, Lukerganj
Allahabad - 211 001
Uttar Pradesh

VOCATIONAL REHABILITATION CENTRE
FOR PHYSICALLY HANDICAPPED
523/L, Model Town
Ludhiana - 141 001
Punjab





Voluntary Health Association of India (VHAI) is a non-profit registered society formed by the federation of Voluntary Health Associations organised at the level of States and Union Territories. VHAI links over 3000 grassroot-level organisations and community health programmes spread across the country.

VHAI's primary objectives are to promote community health, social justice and human rights related to the provision and distribution of health services in India.

VHAI fulfils these objectives through campaigning, policy research, and press and parliament advocacy; through need-based training and provision of information and documentation services; and through production and distribution of innovative health education materials and packages, in the form of print and audiovisuals, for a wide spectrum of users - both urban and rural.

VHAI tries to ensure that a people-oriented health policy is formulated and effectively implemented. It also endeavours to sensitise the largest public towards a scientific attitude to health, without ignoring India's natural traditions and resources.

VOLUNTARY HEALTH ASSOCIATION OF INDIA

Tong Swasthya Bhavan

40 Institutional Area, Behind Qutab Hotel, New Delhi - 110 016, INDIA

Phones : 668071, 668072, 665018, 655871, 652953

Fax : 91-(0)11-6853708