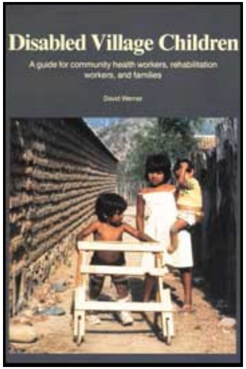

Disabled Village Children - A Guide for Community Health Workers, Rehabilitation Workers, and Families (Hesperian Foundation, 1999, 676 p.)

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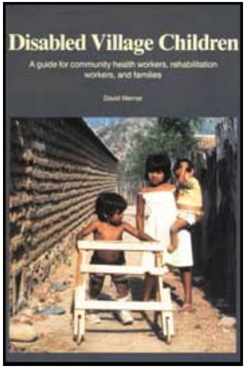
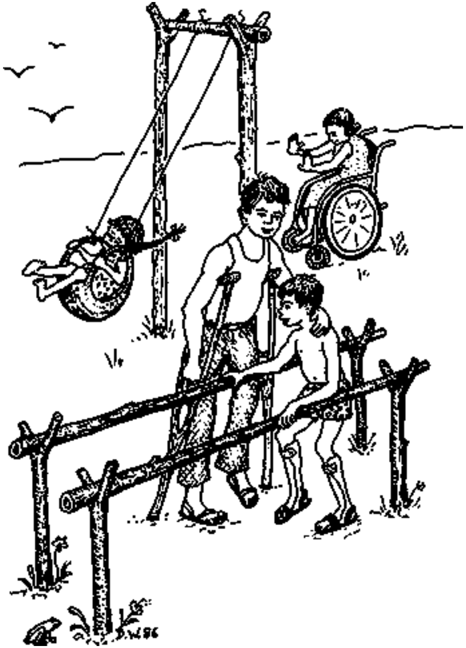


By David Werner
with the help of many friends



Figure

Drawings by the author

Library of Congress Cataloging in Publication Data

Includes Index
1. Medicine, Popular - Handbooks, manuals, etc.
2. Rehabilitation - Handbooks, manuals, etc.
3. Community Health Aids - Handbooks, manuals, etc.

Catalog Card No.: 86-81738

Werner, David, 1943 - Disabled Village Children

Palo Alto, CA: Hesperian Foundation
672 p.
ISBN: 0-942364-06-6

PUBLISHED BY:

The Hesperian Foundation
P.O. Box 11577
Berkeley, CA 94712-2577

2nd edition, 5th printing February 1999

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Please contact the Hesperian Foundation before beginning any translation or adaptation to avoid duplication of efforts, and for suggestions about adapting the information in this book. The Foundation would appreciate receiving a copy of any materials in which text or illustrations from this book have been used.

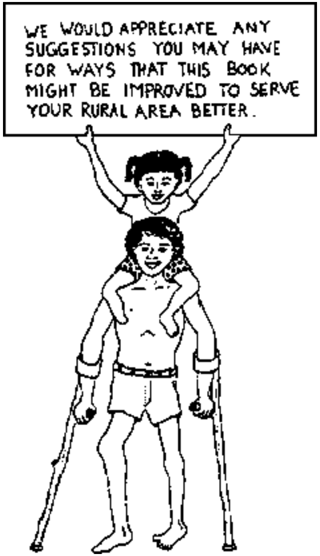
This book is dedicated to disabled children everywhere, with the hope that they and their families will help lead the world to be more loving, understanding, and just for everyone.

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.



Figure

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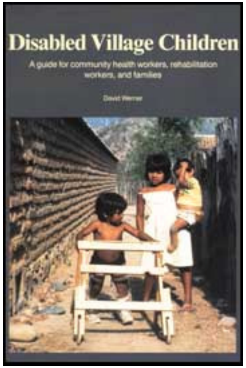


BACK COVER

This book is divided into 3 parts.

PART 1: WORKING WITH THE CHILD AND FAMILY (Chapters 1 to 42)

This is the longest part of the book; divided into 5 sections:

Section A (Chapters 2 to 5): ideas for sharing information from the book; and background information on working with disabled children

Section B (Chapters 6 to 33): detailed information on specific disabilities Section C (Chapters 34 and 35): on the child who is slow to learn and to develop

Section D (Chapters 36 to 41): on helping disabled children become more self-reliant

Section E (Chapters 42 and 43): on learning specific exercises; includes techniques for using crutches, canes, and wheelchairs

PART 2: WORKING WITH THE COMMUNITY (Chapters 44 to 55)

- ideas for starting a community program, and for helping the community respond to the needs of disabled children

PART 3: WORKING IN THE SHOP (Chapters 56 to 67)

- suggestions for setting up a workshop and for making aids, wheelchairs, braces, and rehabilitation equipment

LOOKING UP PAGE REFERENCES

Usually the chapter that discusses a specific disability will not include all the information necessary to meet a child’s needs. You will also have to look in other chapters. There are several ways to find out where to look.

- As you read a chapter, often you will come to page references. This means that you can turn to that page for more information on the topic being discussed.
- To find all the different places in the book that give important information about a specific disability or topic, use the INDEX.
- In some chapters, where further reading is essential, there is a list of references to other parts of the book at the end of the chapter.

It is very important that you learn how to look up these references, and do so. If you do not, the information to meet a child’s needs will not be complete.

REMEMBER: **The best way to learn how to use this book is to work for a while with the guidance of experienced rehabilitation workers.**

Disabled Village Children **is a book of information and ideas for all who are concerned about the well-- being of disabled children. It is especially for those who live in rural areas where resources are limited. But it is also for therapists and professionals who assist community-based programs or who want to share knowledge and skills with families and concerned members of the community.**

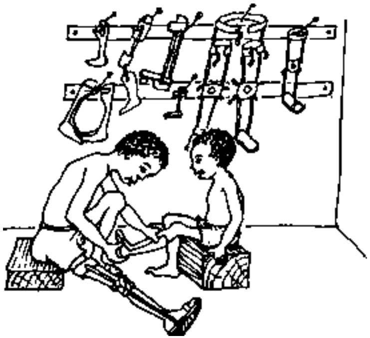
Written by David Werner with the help of disabled persons and pioneers in rehabilitation in many countries, this book has been prepared in a style and spirit similar to the author's earlier works, *Where There Is No Doctor* and *Helping Health Workers Learn.* It gives a wealth of clear, simple, but detailed information concerning most common disabilities of children: many different physical disabilities, blindness, deafness, fits, behavior problems, and developmental delay. It gives suggestions for simplified rehabilitation, low-cost aids, and ways to help disabled children find a role and be accepted in the community.

Above all, the book helps us to realize that most of the answers for meeting these children's needs can be found within the community, the family, and in the children themselves. It discusses ways of starting small community rehabilitation centers and workshops run by disabled persons or the families of disabled children.

Over 4,000 line drawings and 200 photos help make the information clear even to those with little formal education.

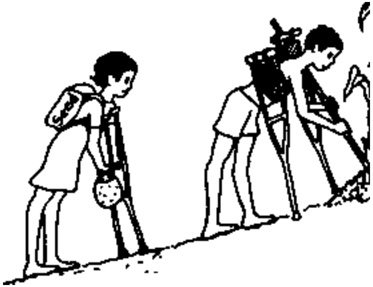
Ways to make therapy fun and useful.

Figure



Brace and limb making in the village

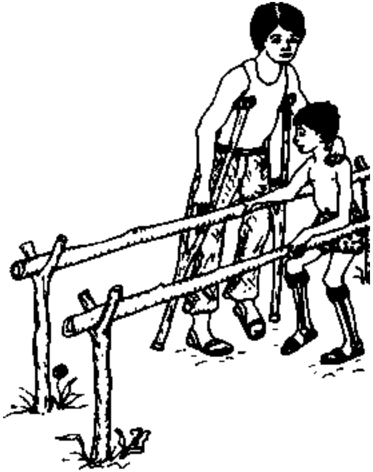
Toy making



Possibilities and adaptations for work

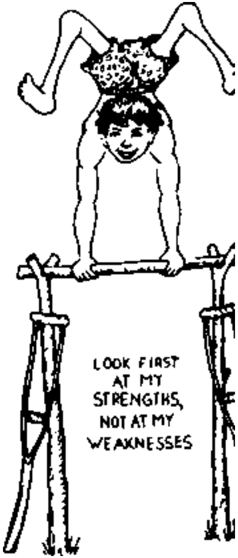
Simple ways to meet basic needs

Adaptations of home and community



Low-cost aids

Children helping children (CHILD-to-child)



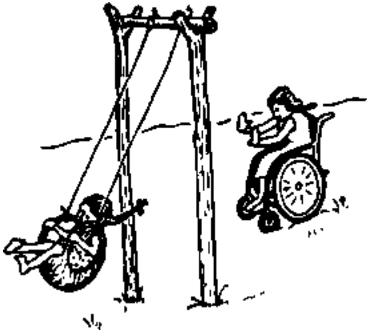
Respect for the abilities of the disabled

Prevention of disability

Stimulation for early development

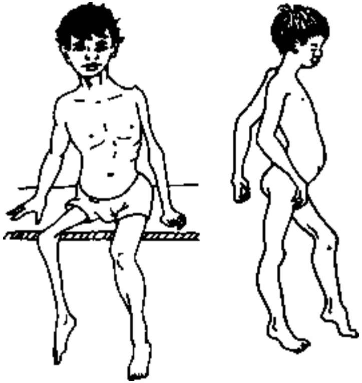
Skills for blind and deaf children

Behavior problems and improvement



Playgrounds for all children

Development of skills for daily living



Identification and management of common disabilities

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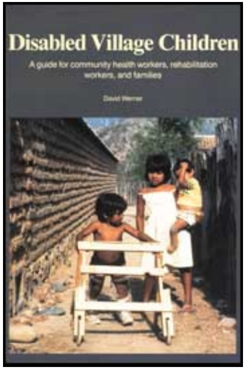


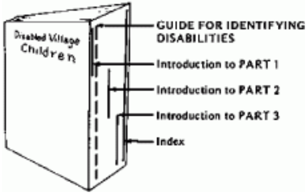
Disabled Village Children - A Guide for Community Health Workers, Rehabilitation Workers, and Families (Hesperian Foundation, 1999, 676 p.)

LIST OF SPECIAL OR DIFFICULT WORDS
BACK COVER

HOW TO USE THIS BOOK

This is a reference book to help you meet the needs of disabled children. You need not read it from cover to cover. Use it to look up particular information as you need it.

To learn how the book is organized, and why, we suggest you read ABOUT THIS BOOK at the beginning. Also, please read the introduction to each of the 3 main parts of the book. These chapters have page edges with a short black line, to help you find the beginning of PARTS 1, 2, and 3.



To work more effectively with disabled children, we strongly suggest that you read the first 5 chapters of PART 1. These will help you to examine a child, to identify different disabilities, and to keep important records in an easy way.

THERE ARE SEVERAL WAYS TO FIND INFORMATION THAT YOU ARE LOOKING FOR:

- **Check the list of CONTENTS at the beginning of the book. This tells you what each chapter is about and gives the page numbers.**
- **Look in the INDEX at the end of the book. It lists topics in alphabetical order.**

(The edges of these pages are all black.)

- **If you do not know what disability a child has, use the GUIDE FOR IDENTIFYING DISABILITIES. It lists the common signs of different disabilities and gives the page numbers. (There are several black lines on the edges of these pages.)**

Throughout the book you will find this symbol (CP) in the margin of some pages. I appears where there is information for *cerebral palsy.*

If you want more information than is in this book, see the list of books and teaching materials entitled REFERENCES (Where to Get More Information).

If you do not know what some words mean, look in the LIST OF SPECIAL OR DIFFICULT WORDS. Words explained in this LIST are written in *italics* when first used in a chapter.

***IMPORTANT:* To find all the information you will need for one disabled child, you will usually need to look in several different chapters. To know where to look, follow the page references shown. These are explained inside the back cover.**

***Asterisk:* This little star is called an asterisk. It is used to indicate that there is more information about a word or an idea at the bottom of the page.**

☞ For more information on how to use this book, see the inside of the back cover.

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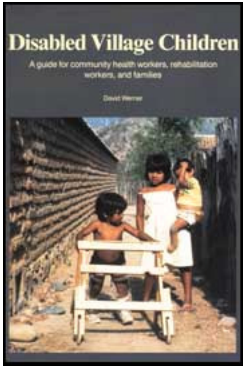
Disabled Village Children - A Guide for Community Health Workers, Rehabilitation Workers, and Families (Hesperian Foundation, 1999,



THANKS

This book has been a cooperative effort. Many persons have contributed in different ways. Some have helped to write or rewrite different sections; some have criticized early drafts; some have used it in their programs and sent us feedback; some have sent original ideas or technologies that we have tested and then included. In all, persons or programs from 27 countries on 6 continents (North and South America, Africa, Asia, Europe, Australia) have contributed.

The entire book has been carefully reviewed by specialists in related fields: physical therapists (PTs), occupational therapists (OTs), orthotists, prosthetists, wheelchair

designers, rehabilitation engineers, and leaders from among the disabled. We cannot include the names of all those who have helped in so many ways, but the help of the following has been outstanding:

Sophie Levitt, PT; Ann Hallum, PT; Terry Nordstrom, PT; Anne Affleck, OT; Mike Miles, rehab planner and critic; Christine Miles, special educator; Farhat Rashid, PT; Bruce Curtis, peer disabled group counselor; Ralf Hotchkiss, wheelchair rider/engineer; Alice Hadley, PT; Jan Postma, PT; Jean-Baptiste Richardier, prosthetist, Claude Simonnot, MD/prosthetist; Wayne Hampton, MD/prosthetist; Jim Breakey, prosthetist; Wally Motlock, orthotist; Valery Taylor, PT; Dr. P. K. Sethi, orthopedic surgeon/prosthetist; Pam Zinkin, pediatrician/CBR expert; Paul Silva, wheelchair builder; David Morley, pediatrician; Ela Landeros, PT; Teresa Pez, social worker; Rafiq Jaffer, rehab specialist; Kris Buckner, parent of many adopted disabled children; Barbara Anderson, PT; Don Caston, rehab engineer; Greg Dixon, Director, Partners' Appropriate Technology In Health; Susan Hammerman, Director, Rehabilitation International; Carole Coleman, specialist in sign language; Suzanne Reier, recreation therapist; Sarah Grossman, PT; Donald Laub, plastic surgeon; Jean Kohn, MD in rehabilitation; Bob Friedricks, orthotist; Katherine Myers, spinal cord injury nurse; Grace Warren, PT in leprosy; Jean M. Watson, PT in leprosy; David Sanders, pediatrician; Jane Neville, leprosy expert; Stanley Browne, MD, leprosy; Alexandra Enders, OT; John McGill, prosthetist; Victoria Sheffield, Rita Leavell, MD, Jeff Watson, J. Kirk Horton, Lawrence Campbell, Helen Keller International; Owen Wrigley, IHAP; Roswitha and Kenneth Klee, Winfried Lichtemberger, Jeanne R. Kenmore, Christoffel Blindenmission; Judy Deutsch, PT; Jane Thiboutot, PT; R.L. Huckstep, MD; Linda Goode, PT; Susan Johnson, PT; David Hall, child health consultant; Ann Goerdt, PT for WHO; Mira Shiva, MD; Nigel Shapcott, seating specialist; Ann Yeadon, educator; Charles Reilly, sign language consultant; Eli Savanack, Gallaudet College; John Gray, MD; Molly Thorburn, MD; Lonny Shavelson, MD; Margaret Mackenzie, medical anthropologist; Rainer Arnhold, MD, Gulbadan Habibi, Caroline Arnold, Philip Kgosana, Garren Lumpkin, UNICEF.

Above all, we would like to thank the team of disabled village rehabilitation workers in Project PROJIMO, Ajoya, Sinaloa, Mexico, along with the hundreds of disabled children and their families. Their involvement and interaction in exploring, testing, inventing, and discovering simplified alternatives has led to the formation of this book. Key among the PROJIMO team are: Marcelo Acevedo, Miguel Alvarez, Adelina Bastidas, Roberto Fajardo, Teresa Grate, Bruce Hobson, Concepcin Lara, Ins Len, Ramon Len, Polo Leyva, Armando Nevrez, Maria Picos, Adelina Pliego, Elijio Reyes, Cecilia Rodrguez, Josefa Rodrguez, Concepcin Rubio, Moiss Salas, Rosa Salcido, Asuncin Soto, Javier Valverde, Florentino Velzquez, Efrain Zamora, Miguel Zamora.

For this book we have borrowed information, ideas, illustrations, methods, and designs from many sources, published and unpublished. Often credit has been given, but not always. If you notice we have ‘borrowed’ from your material and neglected to give you credit, please accept our unspoken thanks and apologies.

For their excellent and dedicated work in preparing the manuscript for publication, special thanks go to: Jane Maxwell, editing, page design, and art production; Irene Yen, editing and paste-up; Kathy Alberts, Elizabeth de Avila, Martn Bustos, Mary Klein, Carlos Romero and Marjorie Wang, paste-up; Martn Bustos and Anna Muoz-Briggs, Spanish translation; Myra Polinger, typing; Lynn Gordon, Bill Bower, Phil Pasmanick and Dan Perlman, general review; Alison Davis, reference section research; Elizabeth de Avila, Don Baker, Agnes Batteiger, Jane Bavelas, Leda Bosworth, Rene Burgard, Michael Lang, Betty Page, Pearl Snyder, Tinker Spar, Paula Tanous and Roger Wilson, proofreading; Lino Montebon, Joan Thompson and David Werner, drawings; Richard Parker, John Fago, Carolyn Watson, Tom Wells and David Werner, photography; Dyanne Ladine, art production; Martn Bustos and Richard Parker, photo production; Hal Lockwood and Helen Epperson of Bookman Productions, Tim Anderson and Linda Inman of Reprographex, typesetting and layout; and Trude Bock for giving so wholeheartedly of herself and her home for the preparation of this book.

We want to give an extra word of thanks to Carol Thuman for coordination, typing, and correspondence and Janet Elliott for graphics, artwork, and paste-up, and to both for sharing the responsibility for the preparation and quality of this book.

The main costs of preparing this book were met by grants from the Public Welfare Foundation, whose continued friendship and support of the Hesperian Foundation's new publications is deeply appreciated. Additional funding was generously provided by the Gary Wang Memorial Fund, UNICEF, OXFAM UK, the Swedish International Development Agency and MISEREOR. We would also like to thank the Thrasher Research Fund and Mulago Foundation for helping meet the costs of Project PROJIMO, from which this book evolved.

For this third printing, we would like to thank Manisha Aryal for coordination; Martin Bustos for meticulous research; Susan McCallister for copy editing and careful proofreading; and Elena Metcalf for page layout and proofreading.

Finally, we would like to thank David Werner for his careful and hard work in preparing this book. His vision and advocacy for disabled people around the world is reflected throughout the book.

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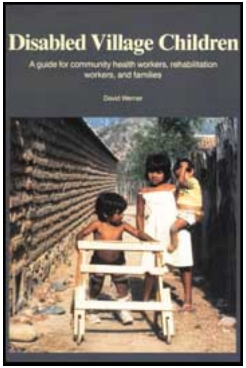
(introduction...)


Disabled Village Children
A guide for community health workers, rehabilitation workers, and families
David Werner

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.

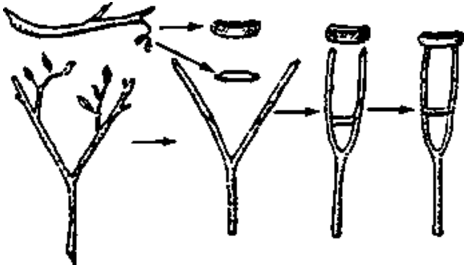
The boy, whose name was Pepe, was sitting on the floor. His legs had been paralyzed by polio, from when he was a baby. Now he was 13 years old. Pepe smiled and reached up a friendly hand.

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.

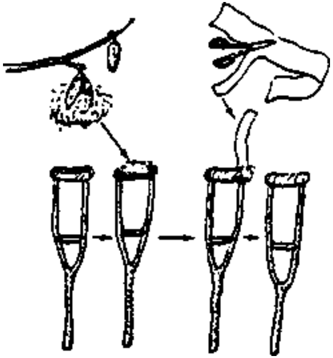
"I tried to tell you they wouldn't work," said the father. "It's the wrong kind of tree. Wood's weak as water! But now I see your idea. I'll go cut some branches of 'jtamo'.

Wood's tough as iron, but light! Don't want the crutches too heavy."

Figure

He took the knife and went into the forest. Fifteen minutes later he was back with 2 forked branches of 'jtamo'. 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.



Figure

“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 the 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 good-bye.

“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 of making crutches before….”

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

Figure

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.

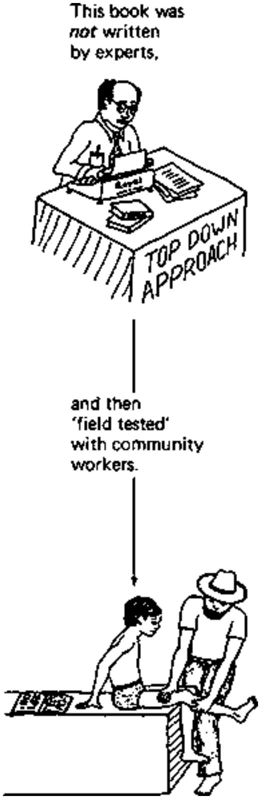
HOW THIS BOOK WAS WRITTEN

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.

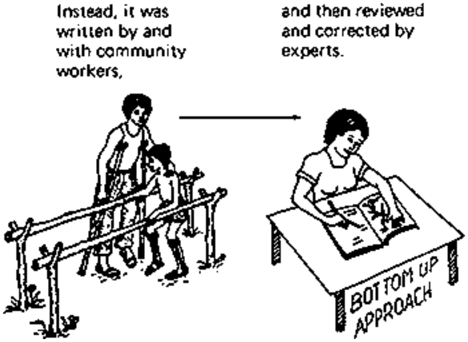
From our experience of trying to help disabled children and their families to meet their needs, we have developed many of the methods, aids, and ideas in this book. We have also gathered ideas from books, persons, and other programs, and have adapted them to fit the limitations and possibilities of our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

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.


This book was *not* written by experts,
TOP DOWN APPROACH
and then 'field tested' with community workers.

Figure



Figure

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 pre-packaged 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.**
- **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 affect 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.

A child who is mentally slow but physically strong,

in a village may not be very handicapped,

but in a city or in school may be very handicapped.

A child who is physically disabled but intelligent,

in a village may be very handicapped,

but in a city or in school may not be especially handicapped.

Figure

The team of disabled village workers in Mexico was at first concerned mostly with physical disabilities. But they soon realized that 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, but only in a very brief, beginner's way. This is partly because we at PROJIMO still do not have much experience in these areas. And partly it is because seeing and hearing disabilities require so much special information that they need to be covered in separate books. Some fairly good instructional material is available on these disabilities, especially on blindness.

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. And except for brief mention, it does ***not*** include very local disabilities such as lathyrism (parts of India). 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 Mexico. 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 advice from persons with more training and experience.**

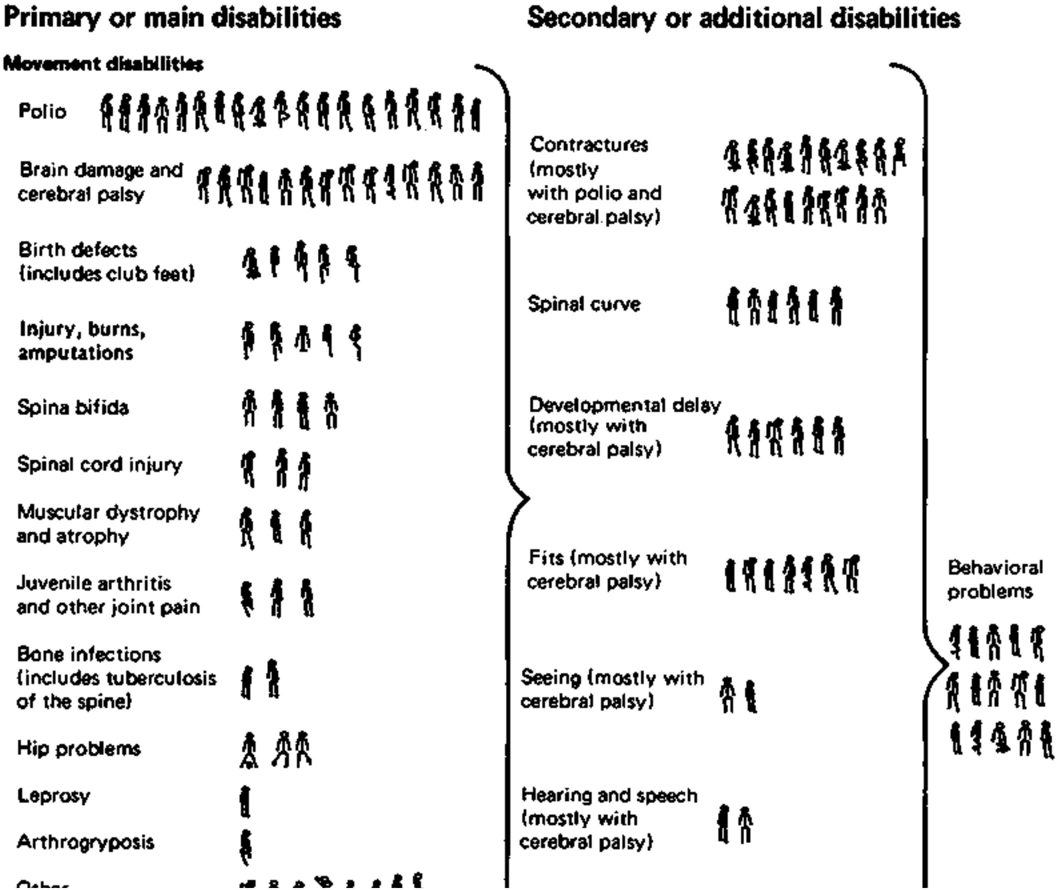
Clearly you cannot solve every problem. But there is much you can do. By asking questions, carefully examining the child, and using whatever information and resources you can find, you may be able to learn much about what these children need and to figure out ways to help them manage better.

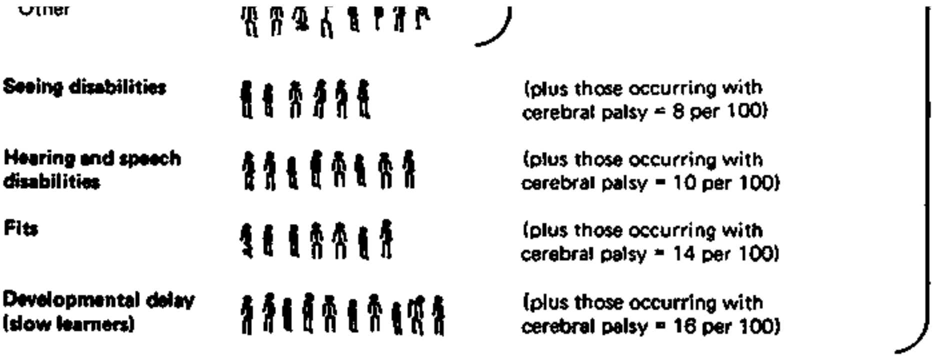
HOW COMMON ARE DIFFERENT DISABILITIES

The little 'stick people' in this chart show how many children might have each disability in an average group 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.

TYPICAL FREQUENCY OF DISABILITIES
PER 100 SIGNIFICANTLY DISABLED CHILDREN

(based on records of 700 children seen at PROJIMO, Mexico)





Figure

***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.**

HOW THIS BOOK IS ORGANIZED

This book is divided into 3 parts: 1, “Working with the Child and Family,” 2, “Working with the Community,” and 3, “Working in the Shop.”

The disabilities that villagers usually consider most important are discussed in early chapters, beginning with Chapter 7. In many countries, more than half of the disabled children have either polio or cerebral palsy. For this reason, we start with them. Other disabilities are arranged partly in order of their relative importance, and partly to place near to each other those disabilities that are similar, related, or easily confused.

Notice that in the chart on p. A8, certain ‘secondary disabilities’ occur very often. (‘Secondary disabilities’ are problems that result after the main disability.) For example,

contractures (joints that no longer straighten) can develop with many disabilities. In many villages, there will be more children who have contractures than who have any single primary disability. For this reason we include some of the important secondary problems in separate chapters.

Common disabilities that are often 'secondary' to other disabilities include:

Contractures, Chapter 8
Dislocated Hips (either a primary or secondary disability), Chapter 18
Spinal Curve (either primary or secondary), Chapter 20
Pressure Sores (often occurs with spinal cord injury, spina bifida, or leprosy), Chapter 24
Urine and Bowel Management (with spinal cord injury and spina bifida), Chapter 25
Behavior Disturbances, Chapter 40

Other disabilities that are often the primary problem but commonly occur with other disability - usually with cerebral palsy - include fits (Chapter 29), blindness (Chapter 30), and deafness and speech problems (Chapter 31).

IMPORTANT: Some important information in this book applies to many disabilities. In order not to make the book longer than it is now, we have not repeated all of this information in each chapter on specific disabilities. Instead we have put it in separate chapters.

This means that **to meet the needs of a specific child, you will often have to look in several different chapters.** We have tried to make this as easy for you as possible (see "How To Use This Book," inside the back cover).

☞ FOR MANY DISABILITIES IT IS VERY IMPORTANT THAT YOU READ INFORMATION FROM SEVERAL CHAPTERS.

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 practice 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. Others 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 exercises 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 56). 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 built 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.

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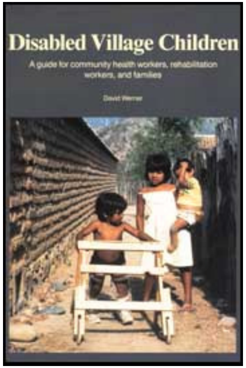


B. Recognizing, Helping with, and Preventing Common Disabilities

Disabled Village Children - A Guide for Community Health Workers, Rehabilitation Workers, and Families (Hesperian Foundation, 1999, 676 p.)

PART 1: WORKING WITH THE CHILD AND FAMILY: Information on Different Disabilities

Figure

Photo by John Fago

Figure

Photo by John Fago

Chapter 1: Introduction to PART 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.

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.

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 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.

All children, as much as possible, should get the exercise they need through daily work and play. (Morocco. Photo by Charles Trieschmann)

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. 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 thing 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

Photo: Cheyne Walk Spastic’s Centre

(b) in a village home

Photo: PROJIMO, Ajoya, Mexico

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.

CP

Maricela 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.

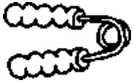
Figure

Her family saved money and took Maricela to a rehabilitation center in the city. After a long wait, a therapist examined her. He explained that Maricela 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.

Figure

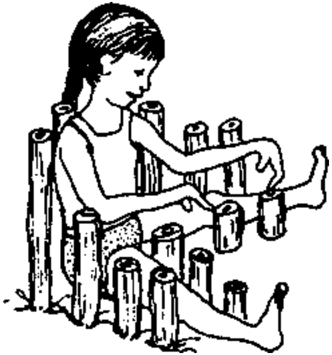
He said she also needed exercises to strengthen and increase the control of her hands and arms.



Figure

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

Maricela’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.

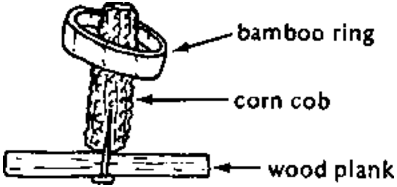


Figure

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

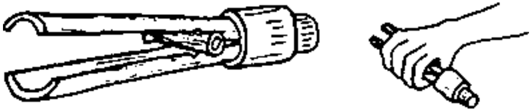
Then, using a board, corn cobs and rings cut from bamboo, he added a small table so that she could play games to develop hand control.

Figure



Figure

He also made a hand exerciser out of bamboo.



Figure

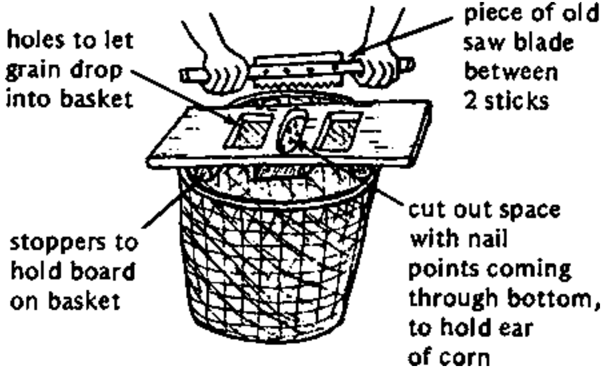
At first, while they were strange and new, Maricela used her special seat and played with her special toys. But soon, she got bored and stopped using them. She wanted to do the things that other children did. She wanted to go with her father and brother to the cornfield. She wanted to help her mother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

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.

Figure

Her parents then visited a small rehabilitation center in a neighboring village. The village team suggested that they look for new ways to help Maricela 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 Maricela 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.



Figure

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.

Figure

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

Maricela’s mother sometimes invited her to help wash the clothes at the river. Maricela 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.

Figure

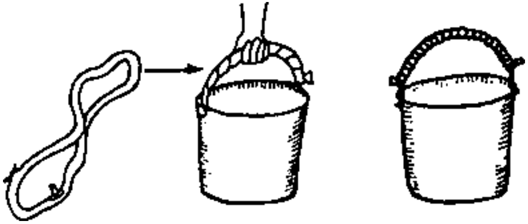
The rock kept her knees apart and the squeezing and banging strengthened her hands and improved her control. But what mattered was getting the clothes clean. It was hard work. But she found it easy - and fun!

Coming back from the river, Maricela 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!

Figure

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

To help Maricela 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 Maricela’s hand sweated, the smooth rubber got slippery. So her father wound a thin rope around the rubber. This way, Maricela could hold it better.



Figure

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 Maricela was stubborn - and she did it! Maricela 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.

Figure

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

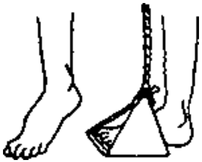
Maricela did learn to walk better, and to use her hands and arms to do many things. But this took a long time. Sometimes she would try something that was too hard, and almost give up. But when her little brother would say she could not do it, she would keep trying until she succeeded.

Even when Maricela 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, Maricela 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.

Figure

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.



Figure

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

After Maricela 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.

Figure

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, Maricela 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 Maricela 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 most anything she wanted or needed to.

Figure

The example of Maricela’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.

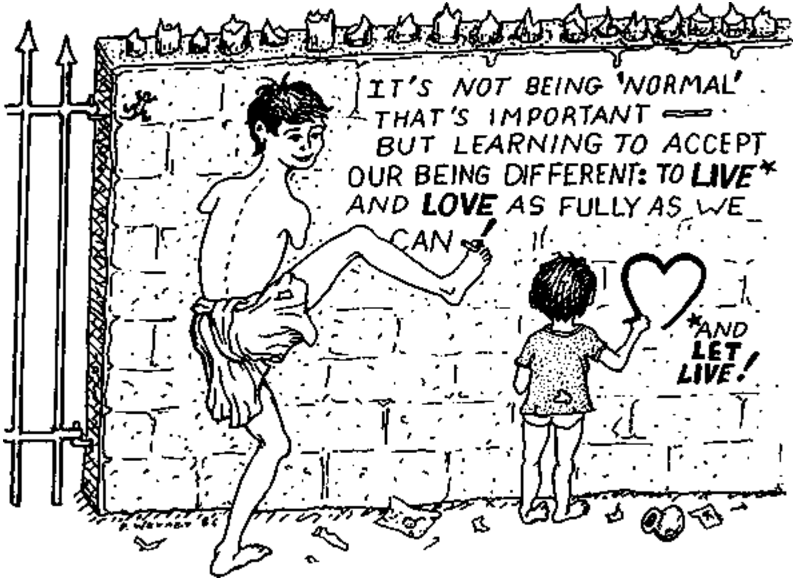
Recently, some ‘appropriate technology’ groups have tried to adapt standard ‘rehabilitation aids’ to poor rural communities. However, many of their designs are modeled fairly closely after the same old city originals, using bamboo and string instead of plastic and aluminum. Some of these low-cost designs 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 fishing camp.

Maricela’s family did just this. The basket of corn, the washing rock, the rocking horse,

and the donkey all became ‘therapy aids’ to help Maricela 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 Maricela’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.



Figure

A. Where Do We Start?

Chapter 2: Ideas for Sharing Information from This Book

Most of the information in this book will be useful to health workers and village rehabilitation workers 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.

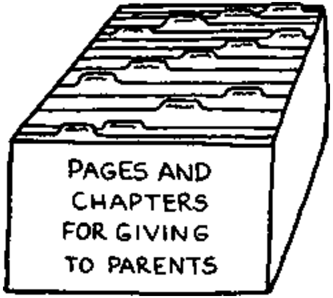
Also, learning from a book is often not the best way to learn something. A lot of methods, aids, and exercises can be learned more easily from other persons, through watching and through guided practice. But after a village worker has taught parents how to do certain exercises, or shown them an example 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 42, and the “Information Sheet on Aspirin”. 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 a young child who is slow to develop, you may want to give pages from the chapters on child development and early stimulation activities (Chapters 34 and 35). For a more advanced child you could give the family material from the chapters on self-care (Chapters 36 to 39).

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 42 were originally prepared separately to give to families. Later, we decided to include them in this book.)



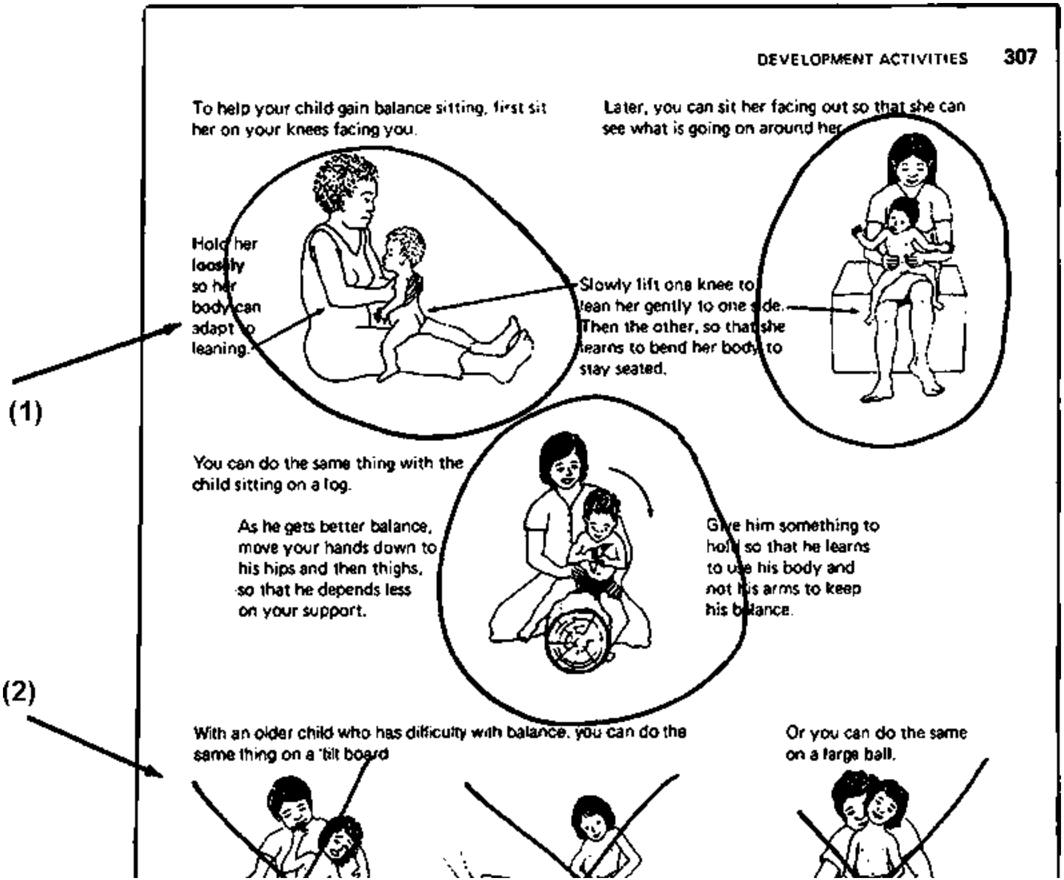
Suggestion: Keep a file of pages, chapters, and information sheets to give to families.

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 (1) 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.(2)



DEVELOPMENT ACTIVITIES 307

To help your child gain balance sitting, first sit her on your knees facing you.

Later, you can sit her facing out so that she can see what is going on around her.

Hold her loosely so her body can adapt to leaning.

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.

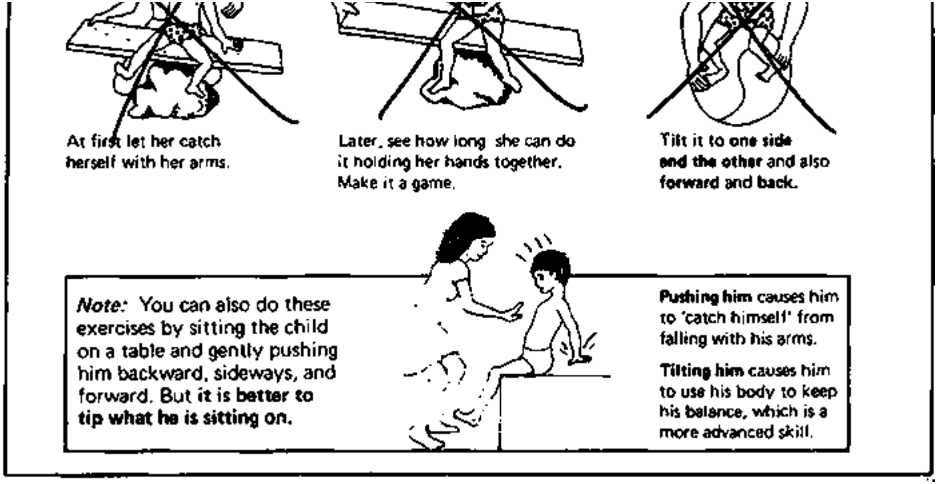
You can do the same thing with the child sitting on a log.

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 dificulty with balance, you can do the same thing on a 'tilt board'

Or you can do the same on a large ball.



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.

Tilt it to one side **and the other** and also **forward and back.**

Note: You can also do these exercises 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.

Figure

Here is an example. If the child is spastic and beginning to sit, the first 3 activities 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 book. 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.*

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

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

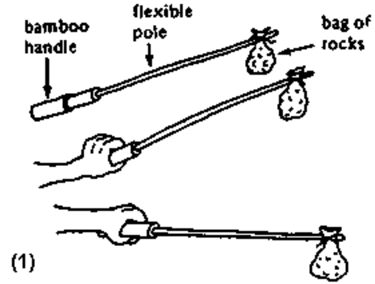
If someone prepares a set of large drawings in advance, perhaps a disabled child who visits the village center can trace the drawings of exercises he needs to do at home. Giving the child this responsibility from the start makes it more likely that he will do the exercises at home.

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.

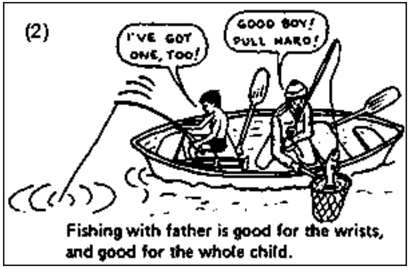
Whatever you do, try to keep both your language and drawings simple and clear. Avoid unfamiliar words.

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

For example, (1) 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, (2) 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.



Figure



Figure

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 exercises

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.

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 book is to:

1. SHOW other people how to do things.

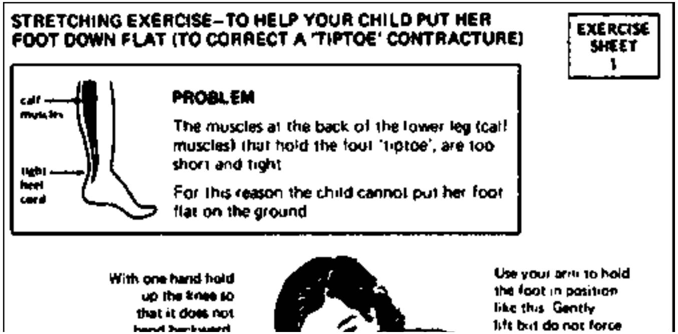
Village rehabilitation workers and family members learn in an outdoor class. Here they practice a hip-stretching exercise. Behind them, drawings on the blackboard show which

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

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

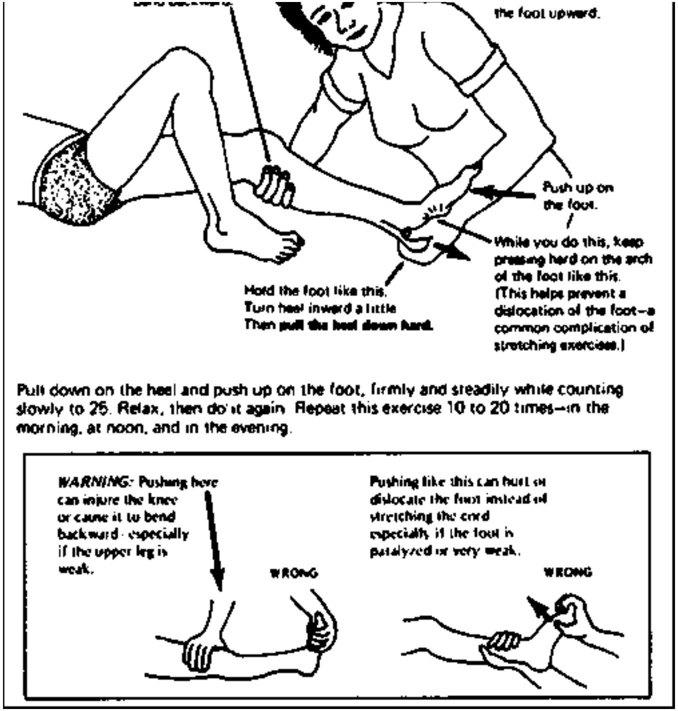
PROBLEM

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



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.

Figure

***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.)**

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.

Figure

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

Figure

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

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

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.

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

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.)

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.**
- ♦ **by not letting their children get unnecessary injections.**

• 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.

• 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.

• Blindness in young children in some countries is caused by not eating enough foods with

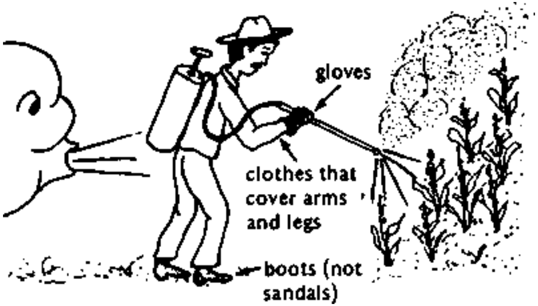
vitamin A. Again this relates to poverty. However, many people do not know that they can prevent this blindness by feeding their children dark green leafy vegetables, yellow fruits, or even certain weeds and wild fruit. Also, some kinds of deafness and mental retardation can be prevented by using iodized salt during pregnancy.

- **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 villagers 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.**

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.

TO PROTECT AGAINST PESTICIDE POISONING

- Stand so that wind blows spray away from you.
- Wear protective clothing, covering the whole body.



Figure

- Wash whole body and change clothes immediately after spraying.

- Wash clothes after spraying.

- Do not let wash water get into drinking supply.

- Do not use spray containers for food or water.

- Do not let children play with spray containers.

> ***CAUTION:*** Make sure that children, and women who are pregnant or breast feeding, stay away from all pesticides.

- **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.**

- **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.***

> ** *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.**

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. (A good book discussing dangerous medicines in poor countries is *Bitter Pills* by Dianna Melrose.)**

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

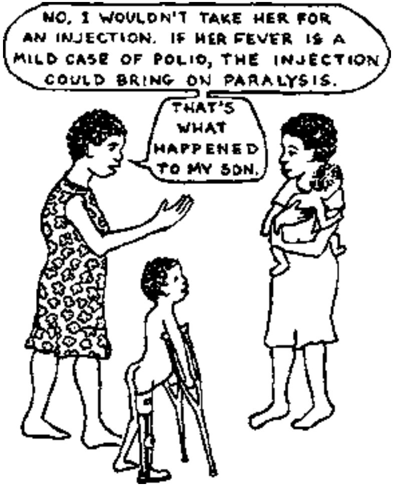
Notice that many of the specific preventive measures we have discussed, just like the more general social measures, depend on increased awareness, community participation, and new ways of looking at things. These changes do not just happen. They require a process of education, organization, and struggle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

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.

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

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



Figure

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. 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.

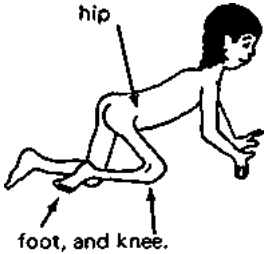
PREVENTING SECONDARY DISABILITIES

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.

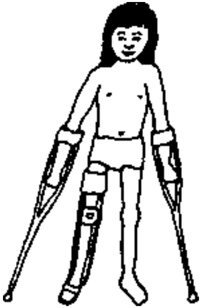
By ‘secondary’ disabilities we mean further disabilities or complications that can appear after, and because of, the original disability.

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 42. Use of plaster casts to correct contractures is described in Chapter 59.

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. 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.**
- **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.**
- **Some braces or aids that help a child at first, may later actually hold her back.**

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).

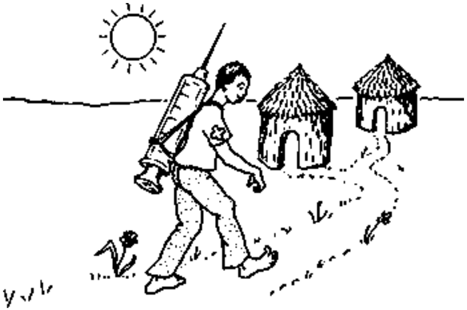
Some disabled children develop serious behavior problems. This is often because they find their bad behavior brings them more attention and ‘rewards’ than their good behavior. Chapter 40 discusses ways that parents can help prevent tantrums and bad behavior in disabled children.

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.

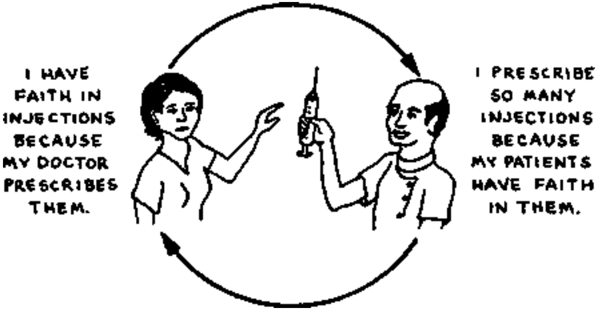
THE NEED FOR MORE SENSIBLE AND LIMITED USE OF INJECTIONS

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). 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.



Figure

HOW INJECTIONS DISABLE CHILDREN

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, 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.

Figure

Figure

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.

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.

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

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 or '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 paralysis from 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.

Combatting misuse and overuse of medicines is as important a preventive measure as is

vaccination, clean water, or the correct use of latrines.

Health workers, schoolteachers, 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

Armed violence is increasing. Since 1980, 45 countries have been involved in 40 wars, with over four million soldiers. 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. Today, 80 to 90 percent are 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. There are 25 to 30 million refugees, many living under dangerous and unhealthy conditions. One-third of the world’s children lack adequate food and basic health care. Millions are homeless. Yet in 1985, world leaders spent 1,000 billion US dollars on war and arms - twice as much as in 1981.

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)

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 dictators 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.

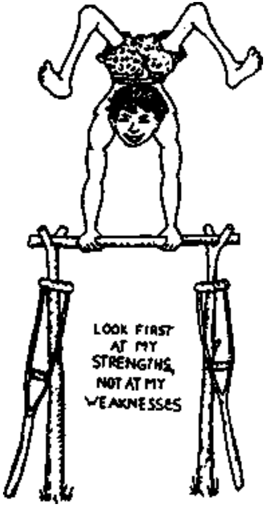
To help change this situation, we disabled persons of the world must join with all who are disadvantaged or treated unfairly, to struggle for a new, more truly human, world order.

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.

Chapter 4: Examining and Evaluating the Disabled Child

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:



Figure

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?**
- **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 she 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?**
- **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 village 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.

Sample RECORD SHEETS included in this book	RECORD SHEET number
Child history	1

Physical examination	2
Tests of nervous system	3
Factors affecting child development	4
Evaluation of progress	5
Child development chart	6

Six sample RECORD SHEETS are on pages 37 to 41, 50, 292, and 293. 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.

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 37 and 38 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 joints,  the backbone,  and skin? 

- 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 well does the child do things, compared to other local children 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

Juan 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.

Figure

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

However, it would be wise to learn about how Juan’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.

Ana 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.

Figure

Ana 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 Ana’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 Ana, 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.**

Figure

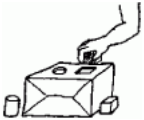
- **If the child seems nervous about a stranger touching or examining her, have the parent do as much of it for you as possible. This will let the mother know that you respect and want to include her. And she may learn more.**

Figure

- **Make the waiting area and place where you do the examining as pleasant and as much like home as you can. Have lots of toys, from very simple to complex, where the children can choose and play with them. By watching if, how, for how long, with what, and with whom a child plays, you can learn a lot about what a child can and cannot do, his level of physical and mental development, the types of problems he has, and the ways he has (or has not yet) adapted to them.**

Figure

Watching how a child plays - by herself, with people, and with toys - is an essential part of evaluating the child.



- **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 a 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

Figure

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, (a) first test the stronger side, (b) and then the weaker side.**

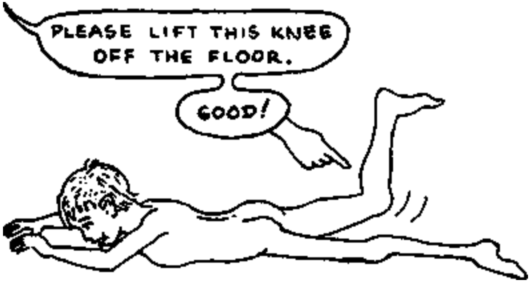


Figure (a)

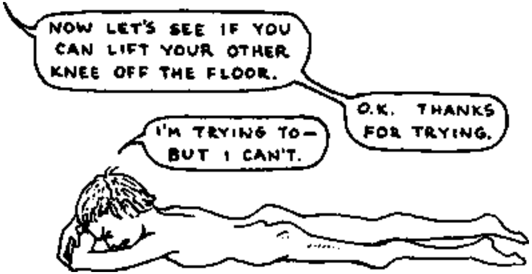


Figure (b)

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.**

Figure

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.

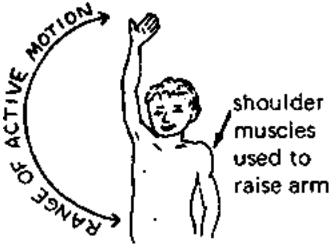
TESTING RANGE OF MOTION OF JOINTS AND STRENGTH OF MUSCLES

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 parts 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		PASSIVE MOVEMENT	
Normally the shoulder muscles can raise the	When the shoulder muscles are	At first the paralyzed arm can be lifted	Unless the normal range of motion is kept through daily

arm until it is straight up.



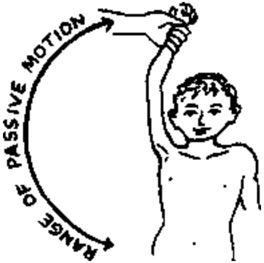
Figure

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

paralyzed, the child can no longer actively lift his arm.

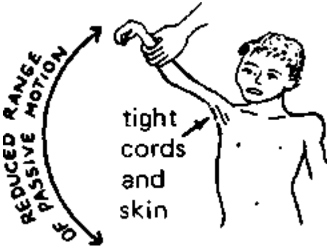
Figure

straight up with help. This is called **PASSIVE MOTION.**



Figure

exercises, the passive range of motion will steadily become less and less.



Figure

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, or 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, casts, 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.

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) in Chapter 42.

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

2. If she cannot straighten it all the

With your

straighten it as much as she can.

Figure

way, gently see how far you can straighten it **without forcing.**

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

Figure

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

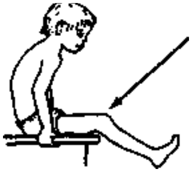
CP 3. If at first the joint will not straighten, keep trying with **gentle continuous pressure** for 2 or 3 minutes.

Figure

Figure

If it gradually straightens, ***spasticity*** (muscle spasms) may be what makes it difficult. (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.



Figure

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

Figure

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**.

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

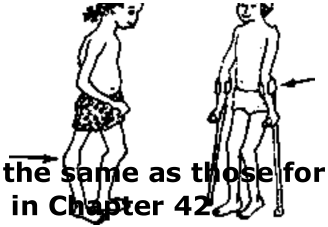
Figure

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).

Figure

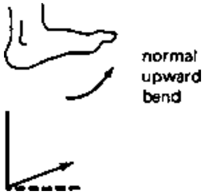
Usually the best positions for checking range of motion are the same as those for doing range-of-motion and stretching exercises. These are shown in Chapter 42.

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



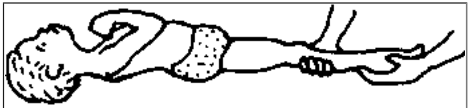
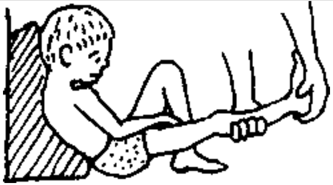
Figure

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

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.

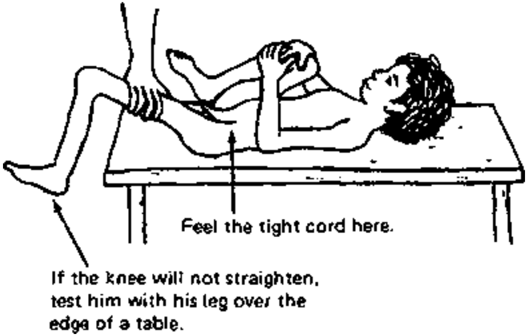
Figure

Figure

Note: To check ankle range of motion in a child with spasticity:		
With his body and knee straight, it 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.
 **Figure**	 **Figure**	 **Figure**
Other precautions for testing ankle range of motion are in Chapter 42		

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.



Figure

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.

Figure

Muscle testing

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

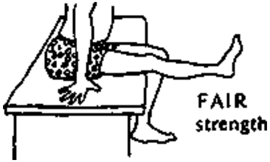
If the child can lift the weight of leg all the way, press down on it, to check if she can hold up as much weight as is normal for a girl her age. If she can, her strength is NORMAL.

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

Figure

Figure

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

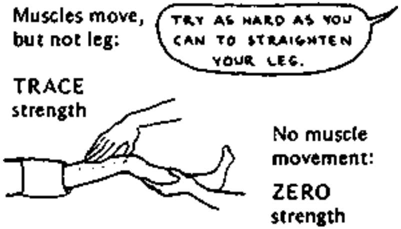


Figure

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.

Figure

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.



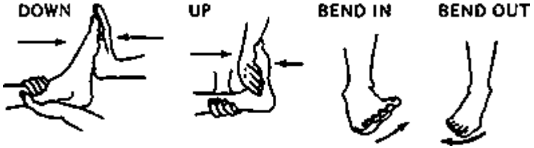
Figure

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



Figure

Note: **Sometimes 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,

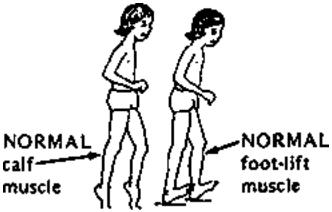
Figure

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

Figure

Also notice if the foot tips or pulls more to one side. This may show ‘muscle imbalance’.

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

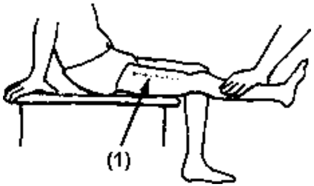


Figure

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.	
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.	

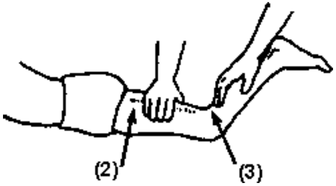
To learn about which muscles move body parts in different ways, as you test muscle strength, feel which muscles and cords tighten.

Knee



STRAIGHTEN

You can fell the muscle tighten on top of the thigh (1).



BEND

Feel the muscles tighten on the back of the thigh (2).

Feel the tight cords pull here (3).

EXAMPLES OF REASONS FOR TESTING

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

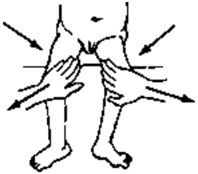
BEND

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

Figure

Hips

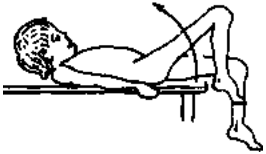
OPENING



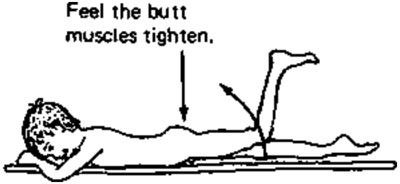
CLOSING

ROTATING HIP OUT (and leg in)

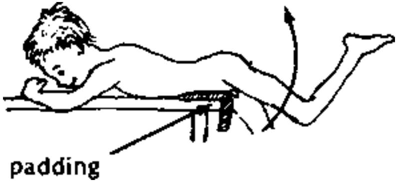
ROTATING HIP IN (and leg out)



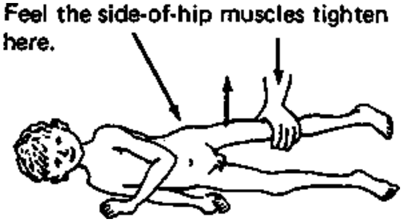
BENDING



STRAIGHTENING



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

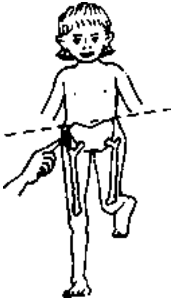
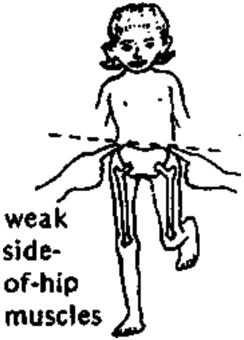


SIDEWAYS LIFT

Note: **Weak hip muscles sometimes lead to *dislocation* of the hip. Be sure to check for this, too.**

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	NOT NORMAL	
The child stands straight. The hip tilts **up** on the lifted leg.	The hip tilts **down** on the lifted side.	Or the child shifts his whole weight so it balances over the weak hip.

 **Figure**	 **Figure**	 **Figure** 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).

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

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

Figure

Figure

Figure

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.

Figure

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

Figure

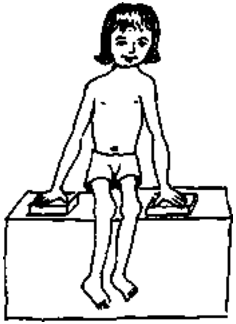
IMPORTANT: Be sure to check for **curvature of the spine -** especially in children with muscle imbalance or weakness of the ***trunk.***

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.

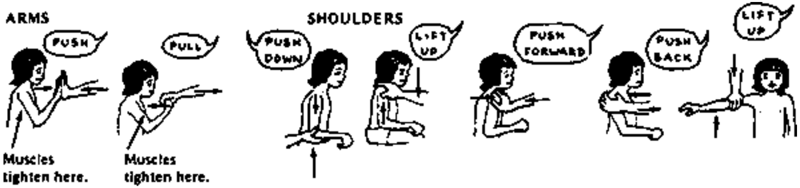
Can she lift her butt off the seat like this?



Figure

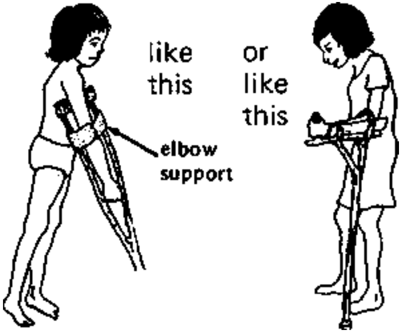
If she can, she has a good chance for walking with crutches.

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



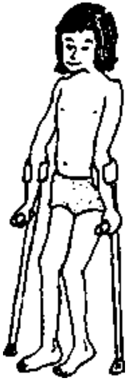
Figure

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.



Figure

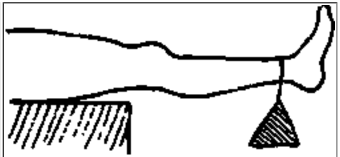
Or, if her elbow range of motion is normal, she may learn to 'lock' her elbow back like this. However, this can lead to elbow problems.

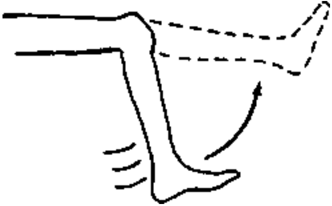


Figure

You may want to make a chart something like this and hang it in your examining area, 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.
In muscle testing, it is especially important to note the difference between FAIR and POOR.	Strong enough to be useful.	NORMAL (5)	lifts and holds against strong resistance	 **Figure**
		GOOD (4)	lifts and holds against some resistance	 **Figure**
		FAIR (3)	lifts own weight but no more	 **Figure**
				Test with the child

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

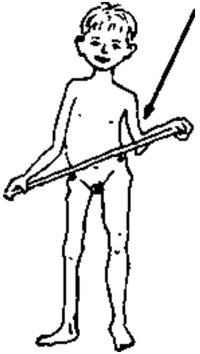
Sometimes with exercise POOR muscles can be strengthened to FAIR; this can greatly

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.

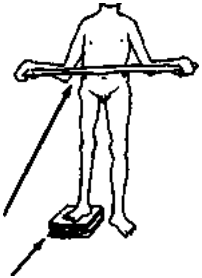
If the child can stand,



look for a tilt of the hip bones,

Figure

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

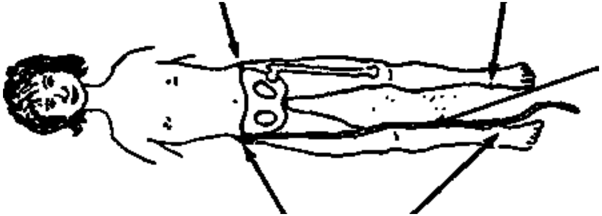


Figure

and measure the difference

If she cannot stand,

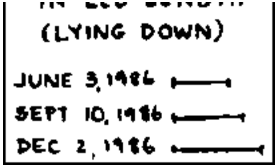
have her lie as straight as she can. Feel and then mark, on both sides of her body, the bony lumps at the top front corner of the hip bone and on the inner ankle.



Pass tape along inner side of knee.

Figure

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.

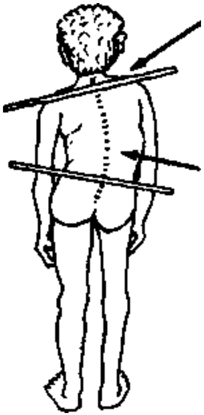


Figure

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:

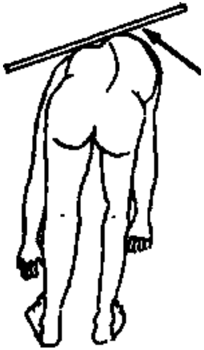
Sideways curve (scoliosis)



shoulder higher on side of short leg

Check for weaker muscles on this side of spine.

Figure



Have the child bend over. Check for a rib hump on outer side of curve.

Figure

Hunch back, rounded back (kyphosis)

May result from weak back muscles, or poor posture.

May result from weak back muscles, or poor posture.

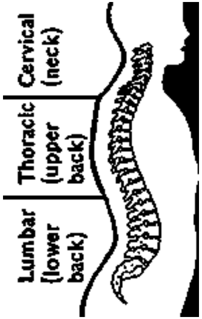
Figure

Sway back (lordosis)

Figure

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.



Normal position of spine showing the 3 main divisions of the backbone.

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 on what part of the nervous system is affected, the disability will have different patterns.

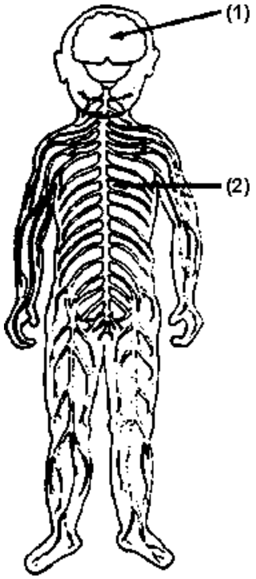
For example, polio affects only certain action nerves at points in the spinal cord (or brain stem). It therefore affects movement. It never affects sensory *nerves,* so sight, hearing, and feeling stay normal. (See Chapter 7.)

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 *from* 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.



Figure

The **brain** (1) is the main control center of the nervous system.

The ‘trunk line’ (2) 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 from 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 wilt 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**
- **fits or seizures (epilepsy) (See Chapter 29.)**
- **balance, coordination, and sense of position**
- **hearing (See Chapter 31.)**
- **use of mouth and tongue, and speech**
- **mental ability; level of development**
- **feeling (pain and touch)**

- **unusual or strange behaviors; signs of self-damage**
- **muscle tone (patterns of unusual floppiness, tightness, spasms, or movements). (See Chapter 9.)**
- **reflexes; muscle jerks**
- **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) may have a head that is bigger than average. If the head continues to grow rapidly, this is a danger sign. 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 41, 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 34 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. 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.

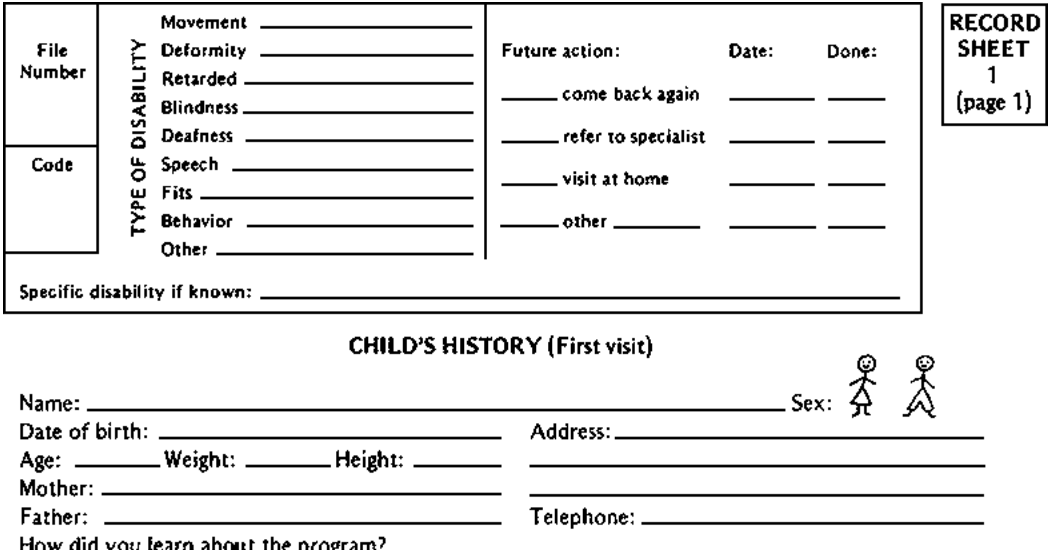
Be sure you have copies made of the RECORD SHEETS you will need *before* you need to use them.

In addition to the 4 RECORD SHEETS here, you may also want copies of RECORD SHEET 5 “Evaluation of Progress,” page 50, and RECORD SHEET 6, “Child Development Chart,” pages 292 and 293.

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.



RECORD SHEET
1
(page 1)

File Number

Code

TYPE OF DISABILITY

Movement ____
Deformity ____
Retarded ____
Blindness ____
Deafness ____
Speech ____
Fits ____
Behavior ____
Other ____

Future action:	Date:	Done:
____ come back again	____	____
____ refer to specialist	____	____
____ visit at home	____	____
____ other ____	____	____

Specific disability if known: ____

CHILD’S HISTORY (First visit)

Name: ____ Sex:
Date of birth: ____
Age: ____ Weight: ____ Height: ____
Mother: ____
Father: ____
Address: ____
____
____
Telephone: ____
How did you learn about the program?

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 the 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? ____________________

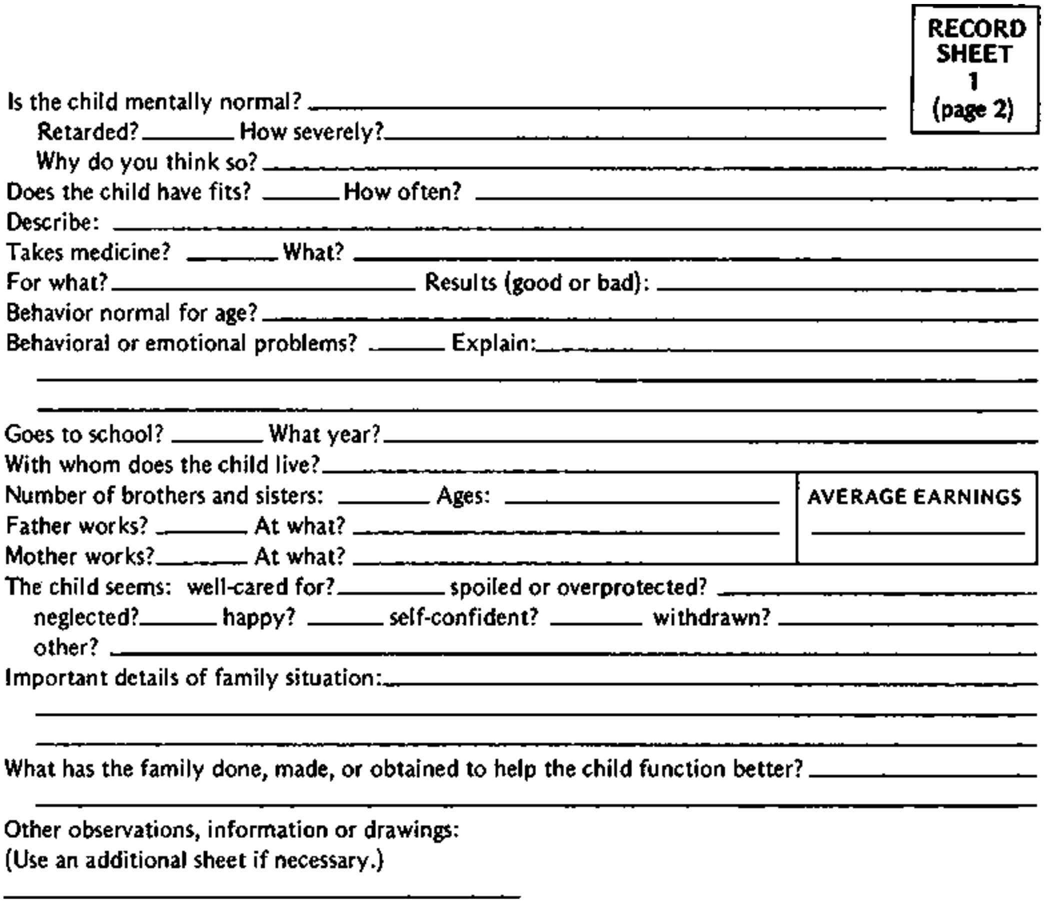
____

What things can the child not do? ____________________

____

What new skills or abilities would you like to see your child gain? ____________________

RECORD SHEET 1 (page 1)



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: ____________

Takes 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? ____________

AVERAGE EARNINGS

____

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.)

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? ______

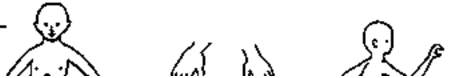
If so, was he or she injected on the side that became most paralyzed? ______

RECORD SHEET 1 (page 2)

SAMPLE RECORD SHEET FOR PHYSICAL EXAM

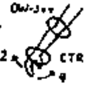
Child's name ______

File number ______



RECORD SHEET 2

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

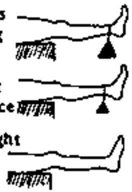
L or R ____________ other ____________ (indicate)

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

Strength or weakness of muscles: Use this code

NORMAL 5	lifts and holds against strong resistance	POOR 2	moves some but cannot lift own weight
GOOD 4	moves against some resistance	TRACE 1	barely moves
FAIR 3	lifts own weight but no more	ZERO 0	no sign of movement



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

R or L	normal	*reduced	*absent
			
			
other			

Problems with

___ *Eyes or sight.
What: ____________
____

___ *Ears or hearing.
What: ____________
____

CTR: contractures

___ tight muscles do not yield with pressure

SP: spasticity

___ *tight muscles yield slowly with pressure

Deep tendon reflexes:

	*nothing 0	*little +	normal ++	*brisk +++	*extreme ++++
Right knee					
Left knee					
Other ______					

Spine

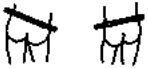
hunchback (kyphosis)

sideways curve (scoliosis)

swayback (lordosis)

hard bump (TB?)

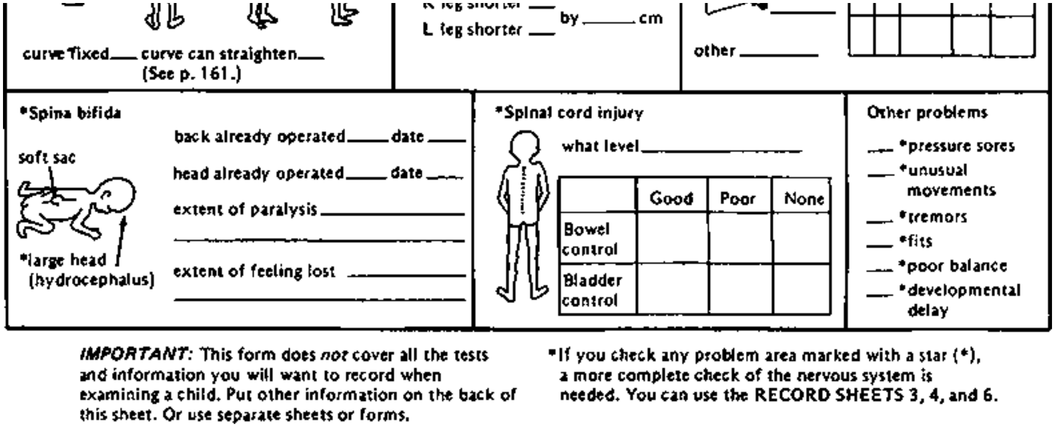
HT: hips tilt



R leg shorter

DL: dislocations:

	R	L	from birth	old	new
hip ______					
knee ______					
elbow					



R leg shorter ___
L leg shorter ___ by ___ cm

curve fixed___ curve can straighten___
(See p. 161.)

other ___

***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			

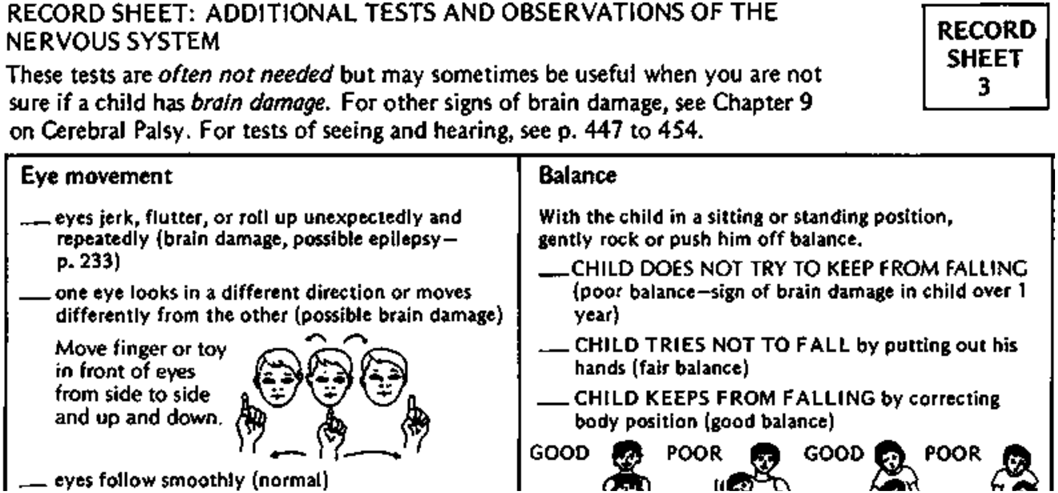
Other problems

___ *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. Put other information on the back of this sheet. Or use separate sheets or forms.

*If you check any problem area marked with a star (*), a more complete check of the nervous system is needed. You can use the RECORD SHEETS 3, 4, and 6.

RECORD SHEET 2



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. 447 to 454.

Eye movement

___ eyes jerk, flutter, or roll up unexpectedly and repeatedly (brain damage, possible epilepsy—p. 233)

___ 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)

Balance

With the child in a sitting or standing position, gently rock 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

___ 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

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

The knee jumps a little.

REDUCED

The leg moves *very little* or not at all.

Typical of polio, muscular dystrophy, and other floppy paralyses.

OVER ACTIVE

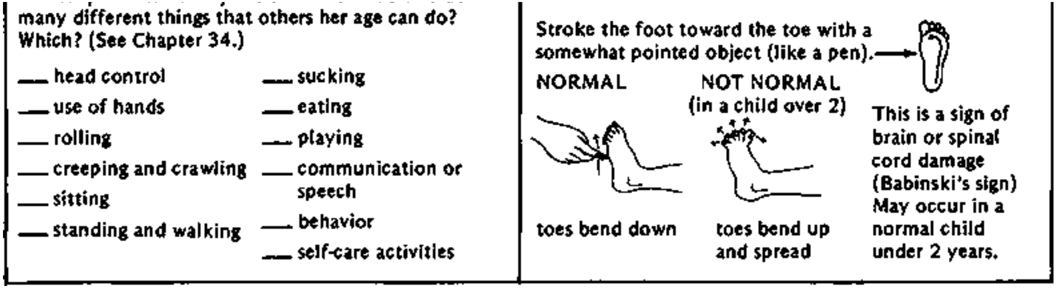
A slight tap causes a *big jump.* Typical of spasticity from cerebral palsy, spinal cord injury, and other brain or spinal cord damage.

KEEPS JUMPING

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



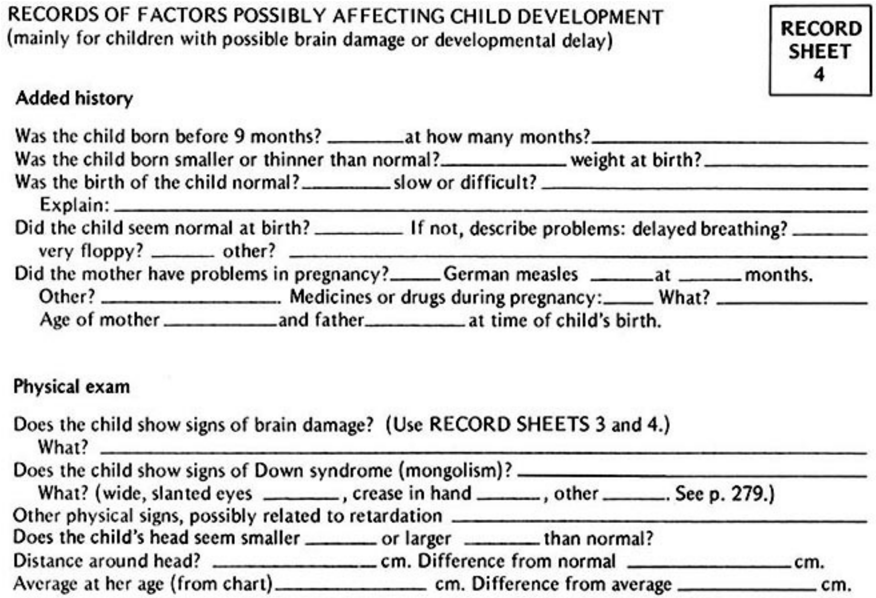
many different things that others her age can do? Which? (See Chapter 34.)

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

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

This is a sign of brain or spinal cord damage (Babinski's sign) May occur in a normal child under 2 years.

RECORD SHEET 3



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. 279.)
Other physical signs, possibly related to retardation ____________________
Does the child's head seem smaller _______ or larger _______ than normal?
Distance around head? _______________ cm. Difference from normal _______________ cm.
Average at her age (from chart) _______________ cm. Difference from average _______________ cm.

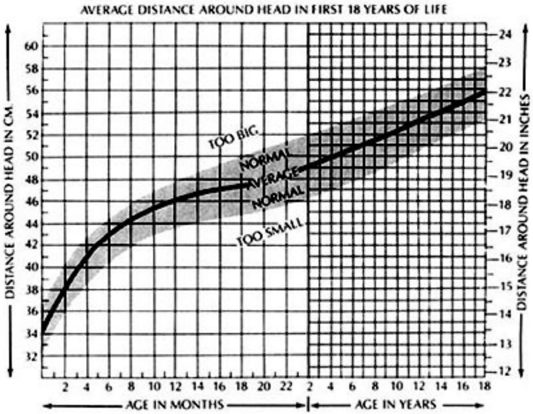
Record of the child's head size

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. 278).

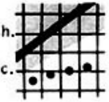
If the dot falls *above* the shaded area, the head is bigger than normal. The child may have **hydrocephalus** (see p. 169).



Note: Boys' heads average from ½ 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. 169). If you do not know how to use the chart, ask a local schoolteacher.

RECORD SHEET 4

Figure

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 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*

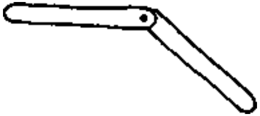
requires knowledge of angles, degrees, and symbols that many people do not understand. For evaluation to become a family tool, we need a way to measure, record, and interpret information that is as simple, clear, and enjoyable as possible. Here are some ideas.

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.)

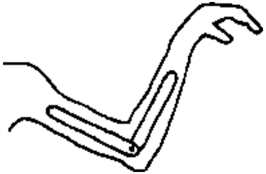
Other simple methods for recording joint positions are in Chapter 9.

1. Rivet the pieces together on one end.



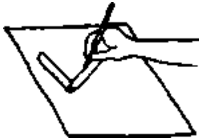
Figure

2. Line them up exactly with the joint.



Figure

3. Trace the angle on paper.



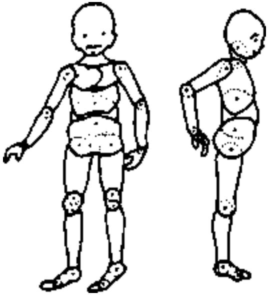
Figure

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

Figure

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.

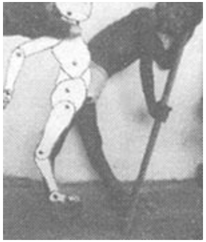
Children making and playing with flexikins. In the PROJIMO village rehabilitation center, all the flexikins used are made by disabled children and the local school children.

Examples of how flexikins are used

Figure

Figure

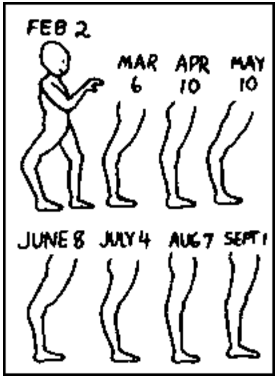
Village rehabilitation workers have just made a brace for a child with polio whose leg bends back severely. They want to know if the leg will gradually get better (bend back less). So they ask the mother to measure it every month.



Figure

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.

Figure

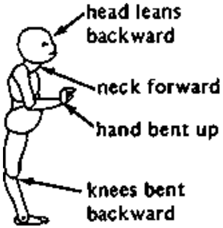


Figure

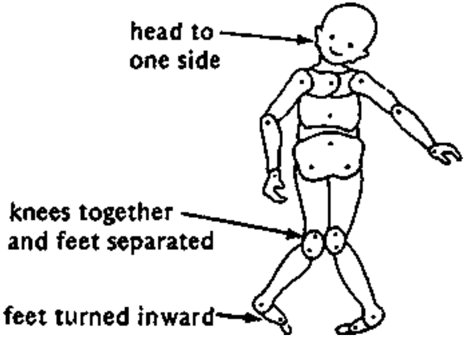
Each month she does the same and records the date. (In April her son did not use the brace for 2 weeks and she saw the knee was getting worse. This convinced both mother and boy of the importance of using the brace.)

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:

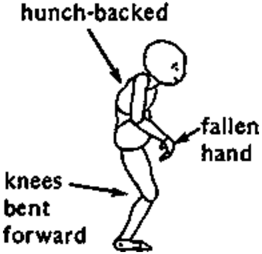
Figure



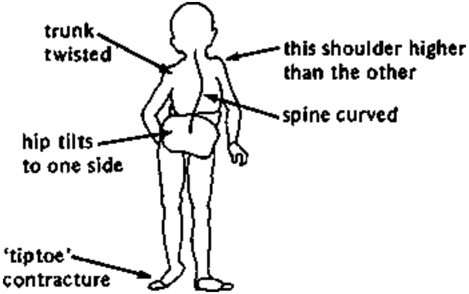
Figure



Figure

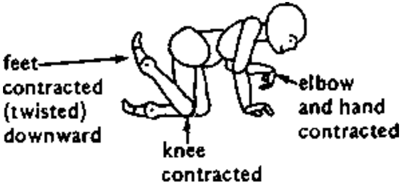


Figure

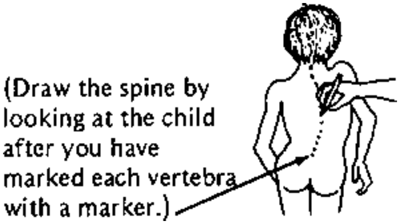


Figure

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



Figure



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

Figure

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.

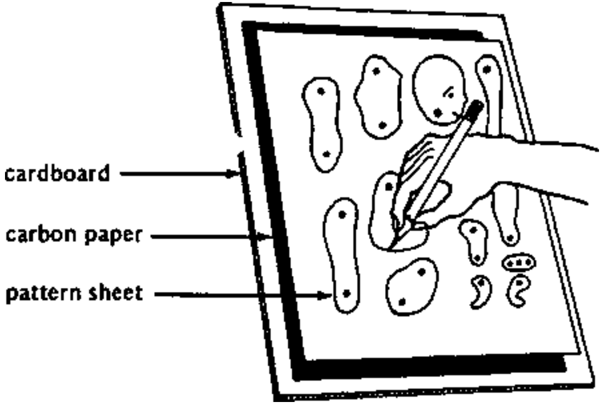
Note: For recording contractures, we have found the side-view flexikin more useful than the front-view one. The side-view flexikin is also easier to make. It is probably the only one you will need for evaluating a child’s progress.

How to make the flexikins

1. Trace the patterns of different pieces 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.)

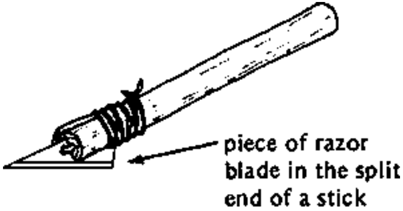
Or you can glue a copy of the pattern sheet directly to the cardboard.



Figure

(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.)

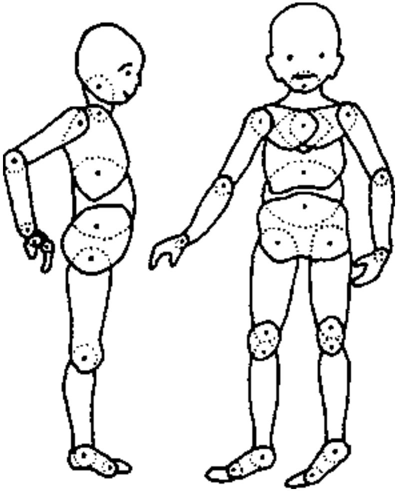
2. Cut out the pieces with strong scissors, shears, or a piece of razor blade.



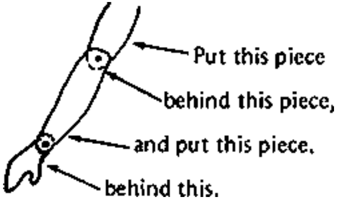
Figure

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.



Figure



Figure

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

Use the smallest rivets you can find.

Figure

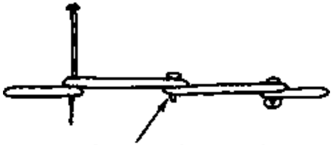
Or string the joints together with thread or yarn (this does not work as well).

Figure

Or use thin wire or string and tie knots.

Figure

Or use sewing pins;



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

Figure

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 w exercises or aids.

We suggest you take a new measurement every ______________________________

Do it like this:

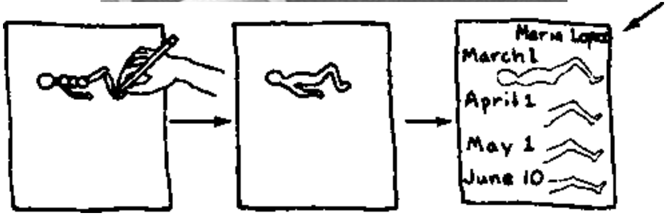
1. Have your child take the position you want to measure (for example, straighten his knee as much as he can).

Figure

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.

Figure

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.



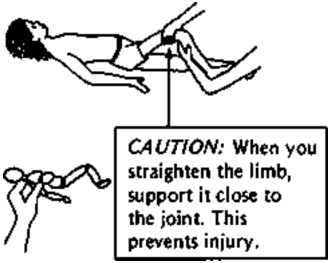
Figure

This example shows how exer
have helped straighten a cont
knee.

For later recordings, you only need to trace the part or parts you are measuring. Each time you record
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).

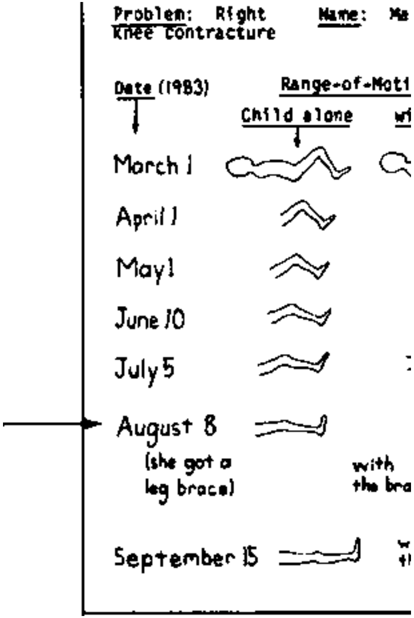
Make 2 columns. In one, record how far the child can move it by herself. In the other column record how far she can move it with help.



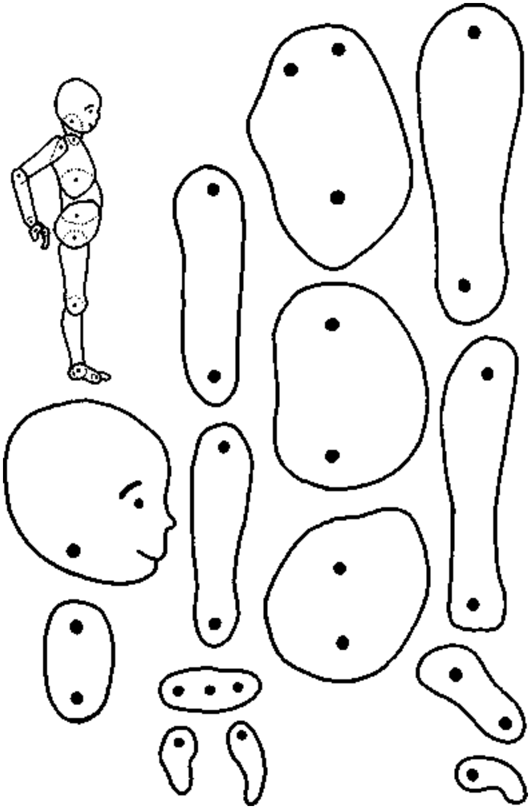
CAUTION: When you straighten the limb, support it close to the joint. This prevents injury.

Figure

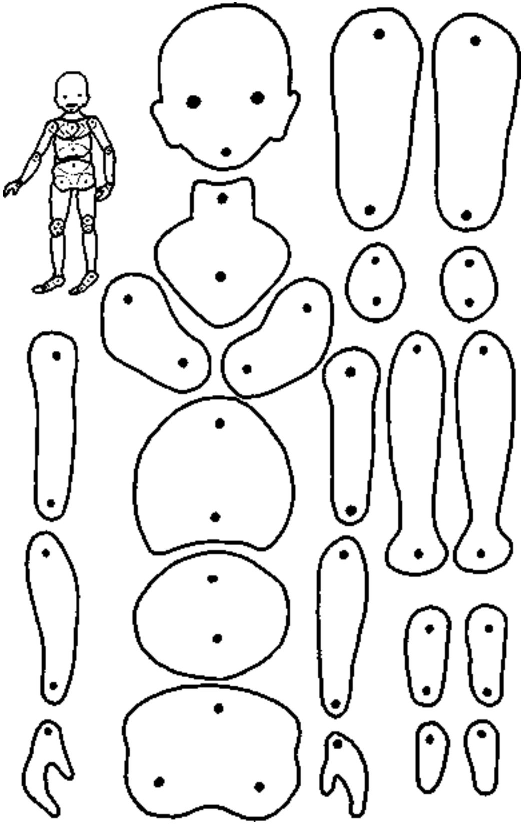
Here you see the progress of a leg until it became straight and a brace could be made for it.



Figure



SIDE-VIEW FLEXIKIN - Patterns of pieces for making it



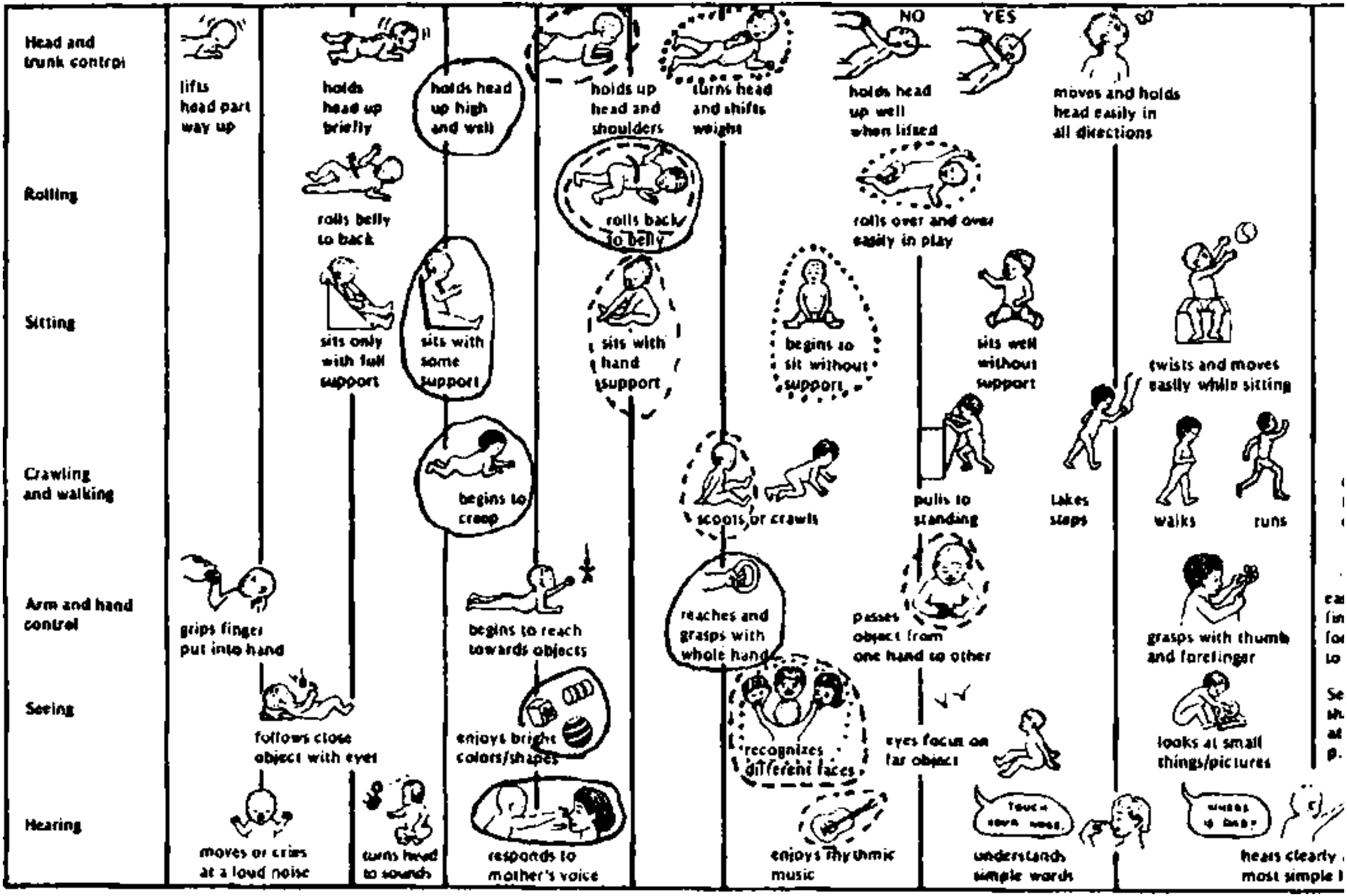
FRONT-VIEW FLEXIKIN - Patterns of pieces for making it

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. 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.


Head and trunk control
lifts head part way up
holds head up briefly
holds head up high and well
holds up head and shoulders
turns head and shifts weight
NO
YES
holds head up well when lifted
moves and holds head easily in all directions
Rolling
rolls belly to back
rolls back to belly
rolls over and over easily in play
Sitting
sits only with full support
sits with some support
sits with hand support
begins to sit without support
sits well without support
twists and moves easily while sitting
Crawling and walking
begins to creep
scoots or crawls
pulls to standing
takes steps
walks
runs
Arm and hand control
grips finger put into hand
begins to reach towards objects
reaches and grasps with whole hand
passes object from one hand to other
grasps with thumb and forefinger
Seeing
follows close object with eyes
enjoys bright colors/shapes
recognizes different faces
eyes focus on far object
looks at small things/pictures
Hearing
moves or cries at a loud noise
turns head to sounds
responds to mother's voice
enjoys rhythmic music
understands simple words
hears clearly
most simple

Figure

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 visits. 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, a little 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!**

RECORD SHEET

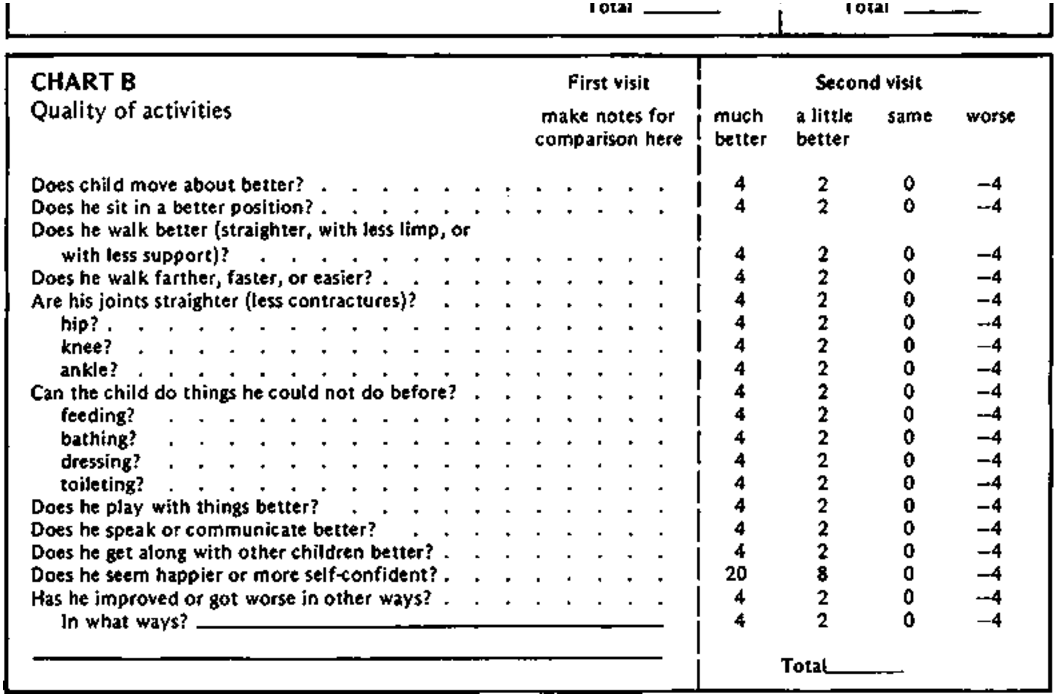
EVALUATION OF PROGRESS – CHILD OVER AGE 5

EVALUATION OF PROGRESS — CHILD OVER AGE 3

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		



Total ______ | Total ______

CHART B
Quality of activities

	First visit	Second visit			
	make notes for comparison here	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______			

RECORD SHEET 5

B. Recognizing, Helping with, and Preventing Common Disabilities

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 we add other signs that can help you tell apart similar disabilities. The third 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.

This 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 similar weakness, and the chapters on other problems that the child may have. For this 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
GUIDE FOR IDENTIFYING AND TREATING DIFFERENT FORMS OF FITS (EPILEPSY)

GUIDE FOR IDENTIFYING DISABILITIES

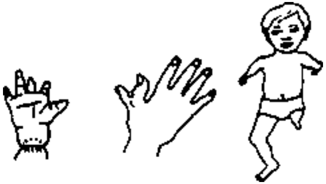
SIGNS PRESENT AT OR SOON AFTER BIRTH

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
born weak or 'floppy'  **Figure**	• often a difficult birth • delayed breathing • born blue and limp • or born before 9 months and very small	• cerebral palsy • developmental delay

slow to begin to lift head or move arms  **Figure**		
	 **Figure** • round face • slant eyes • thick tongue	• Down syndrome (mongolism) • cretinism
	 **Figure** small head, or small top part of	microcephalia (small brain) mental retardation

	head	
	none of above	developmental delay for other reasons
does not suck well or chokes on milk or food  **Figure**	• pushes milk back out with tongue • or will not suck	cerebral palsy
	• cannot suck well • chokes or milk comes out nose	• check for cleft palate  **Figure** • possibly severe retardation
one or both feet turned in or back  **Figure**	no other signs	club foot
	• hands weak, stiff or clubbed • some joints stiff, in bent or	arthrogryposis

	straight positions  **Figure**	
	dark lump on back	spina bifida
‘bag’ or dark lump on back  **Figure**	• clubbed feet • or feet bend up too far  **Figure** • or feet lack movement and feeling	spina bifida (sometimes no ‘bag’ is seen, but foot signs may be present)
head too big: keeps growing	may develop: • eyes like ‘setting sun’	hydrocephalus (water on the brain) At birth, this is usually a sign of spina bifida. in an older child, possibly tapeworm in

 **Figure**	 **Figure** • increasing mental and/or physical disability • blindness	brain, or a brain tumor
upper lip and/or roof of mouth incomplete  **Figure**	• difficulty feeding • later, speech difficulties  **Figure**	cleft lip (hare lip) and cleft palate
birth deformities, defects, or missing parts  **Figure**	(may or may not be associated with other problems)	See • birth defects • amputations • Down syndrome • developmental delay
abnormal stiffness or position	• from birth • some muscles weak • some joints stiff	arthrogryposis

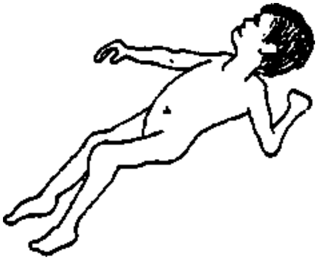
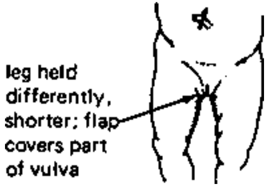
	• head control and mind normal	 **Figure**
Figure	• Muscles tighten more in certain positions. • may grip thumb tightly  **Figure**	spastic cerebral palsy ***Note:*** muscle tightness (spasticity) usually does not appear until weeks or months after birth.
one arm weak or in strange position 	does not move the arm much  **Figure**	Erb's palsy (weakness from damage to nerves in shoulder during birth)

Figure		
	leg on same side often affected	hemiplegic (one-sided) cerebral palsy
dislocated hip at birth  **Figure**	On opening legs like this, leg 'pops' into place or does not open as far.  **Figure**  **Figure**	dislocated hip from birth (often both hips) may be present with: • spina bifida • Down syndrome • arthrogryposis

slow to respond to sound or to look at things  **Figure**	(may be due to one or a combination of problems)	Check for signs of: • developmental delay • cerebral palsy • blindness • deafness

SIGNS IN CHILDREN

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
slower than other children to do things (roll, sit, use hands, show interest, walk, talk)  **Figure**	slow in most or all areas:	Developmental delay, check for signs of:
	• round face • slant eyes • single deep crease in hand	Down syndrome (mongolism)

	 **Figure**	
	• movements and response slow • skin dry and cool • hair often low on forehead • puffy eyelids  **Figure**	cretinism
	has continuous strange movements or positions, and/or stiffness  **Figure**	cerebral palsy also check for: • blindness • deafness • malnutrition

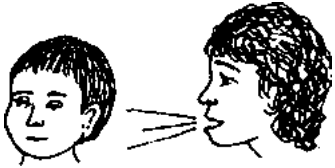
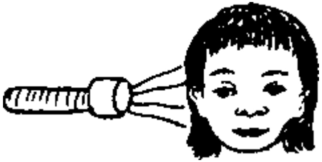
does not respond to sounds, does not begin to speak by age 3  **Figure**	may respond to some sounds but not others Check for ear infection (pus).	Check for: • deafness • severe developmental delay (with or without deafness) • severe cerebral palsy
does not turn head to look at things, or reach for things until they touch her  **Figure**	Eyes may or may not look normal.	• blindness and/or • severe mental retardation • severe cerebral palsy
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

Figure All or part of body makes strange, uncontrolled movements.  **Figure**	• 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.)
	slow, sudden, or rhythmic movements; fairly continuous (except in sleep); no loss of consciousness  **Figure**	athetoid cerebral palsy (***Note*****:** Fits and cerebral palsy may occur in the same child.)
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

	 **Figure**	

PARTS OF BODY WEAK OR PARALYZED

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
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  **Figure** • irregular pattern of parts weakened. Often one or both legs - sometimes arm, shoulder,	polio

	hand, etc.	
	• begins little by little and steadily gets worse • about the same on both sides of body • often others in the family also have it  **Figure**	• muscular dystrophy • muscular atrophy
	 **Figure** • Paralysis starts in legs and moves up: may affect whole body. • or, pattern of paralysis variable	tick paralysis  **Figure** Guillain-Barr paralysis (usually temporary) paralysis from pesticides, chemicals, foods (lathyrism)

	lump on back	tuberculosis of spine
floppy or limp weakness usually **some loss of feeling**	• one or both hands or feet  **Figure** • develops slowly in older child. Gets worse and worse.	leprosy
	• born with bag on back (Look for scar.)  **Figure** • feet weak, often without feeling	spina bifida  **Figure**
	• 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)**
	injury to nerves going to one part of body	hand weakness sometimes caused by using crutches wrongly
weakness usually **with stiffness or spasticity of muscles** **no loss of feeling**	usually affects body in one of these patterns  **Figure**	• 1: cerebral palsy (or stroke, usually older persons) • 2 and 3: cerebral palsy • occasional other causes

	Muscles tighten and resist movement because of joint pain.	JOINT PAIN (many causes - see below)

JOINT PAIN

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
one or more painful joints	• begins with or without fever • gradually gets worse, but there are better and worse periods  **Figure**	juvenile arthritis
		other causes of joint pain See chart on joint pain.

WALKS WITH DIFFICULTY OR LIMPS

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
dips to one side with each step	one leg often weaker and shorter	Check for:

 **Figure**		• polio • cerebral palsy • dislocated hip
	• usually begins age 4 to 8 • may complain of knee pain	damaged hip joint
walks with knees pressed together  **Figure**	• muscle spasm and tightness • upper body little affected	spastic diplegic or paraplegic cerebral palsy
stands and walks with knees together and feet apart	feet less than 3” apart at age 3	normal from ages 2 to 12

 **Figure**	 **Figure**	
no other problems	feet more than 3” apart at age 3  **Figure**	knock-kneed
walks awkwardly with one foot tiptoe	muscle spasms and poor control on that side. Hand on that side often affected.	hemiplegic cerebral palsy (stroke in older persons)

		
walks awkwardly with knees bent and legs usually separated  **Figure**	• jerky steps, poor balance • sudden, uncontrolled movements that may cause falling	athetoid cerebral palsy
	• slow ‘drunken’ way of walking • learns to walk late and falls often	• poor balance (ataxia) - often with cerebral palsy • Down syndrome (mongolism) • cretinism
walks with both feet tiptoe	• weakness, especially in legs and feet • gradually gets worse and worse	muscular dystrophy

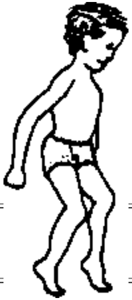
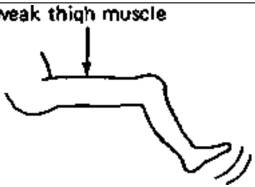
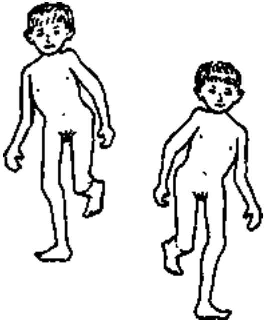
 **Figure**		
	legs and feet stiffen (spasticity of muscle)	spastic cerebral palsy
	no other problems	normal? (some normal children at first walk on tiptoes)
walks with hand(s) pushing thigh(s) or with knee(s) bent back  **Figure**	 **Figure** difficulty lifting leg	• polio • muscular dystrophy • arthritis (joint pain) • other causes of muscle weakness
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 • nerve or muscle injury

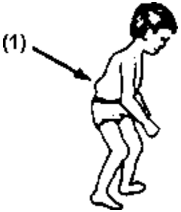
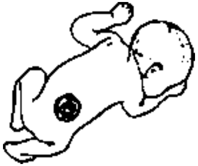
 **Figure**	 **Figure**	• other cause of weakness
dips from side to side with each step  **Figure**	due to muscle weakness at side of hips, or double dislocated hips, or both	• polio • cerebral palsy • spina bifida • Down syndrome • muscular dystrophy • child who stays small • arthrogryposis • dislocated hips (may occur with any of the above)
walks with one (or both) hip, knee, or ankle that stays bent	joints ***cannot*** be slowly straightened when child relaxes	• contractures (shortened muscles) • joined or fused joints may be secondary to: • polio • joint infection

		• other causes
	Joints ***can*** gradually be straightened when child relaxes.	spasticity, often cerebral palsy
Knees wide apart when feet together (bow legs). Waddles or dips from side to side (if he walks). **Figure**  **Figure**	under 18 months old	often normal
	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’.	Consider: • rickets (lack of vitamin D and sunlight) • brittle bone disease • children who stay very short (dwarfism) • cretinism • Down syndrome

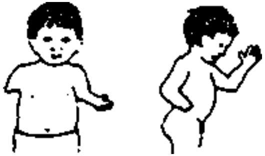
	- Belly and butt stick out a lot.  **Figure**	- dislocated hips
flat feet  **Figure**	no pain or other problems	normal in many children
	- Pain may occur in arch of foot. - Deformity may get worse.	may be problems in: - cerebral palsy - polio - spina bifida - Down syndrome

BACK CURVES AND DEFORMITIES

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
sideways curve of backbone  **Figure**	When child bends over, look for a lump on one side.  **Figure**	‘scoliosis’ - may occur alone or as complication of: • polio • cerebral palsy • muscular dystrophy • spina bifida • other physical disability
sway back  **Figure**	• belly often sticks out • may be due to (1) 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
rounded back		‘kyphosis’ - often occurs with:

 **Figure**		• arthritis • spinal cord injury • severe polio • brittle bone disease
(1) hard, sharp bend of or bump in backbone  **Figure**	• starts slowly and without pain • often family history of tuberculosis • may lead to paralysis of lower body	tuberculosis of the spine
dark soft lump over backbone  **Figure**	• present at birth • sometimes only a soft or slightly swollen area over spine • weakness and loss of feeling in feet or lower body	spina bifida ('sack on the back')

OTHER DEFORMITIES

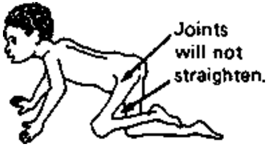
IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
missing body parts	born that way  **Figure**	born with missing or incomplete parts
	accidental or surgical loss of limbs (amputation)  **Figure**	amputations
	gradual loss of fingers, toes, hands, or feet, often in persons who lack feeling  **Figure**	• osteomyelitis (bone infections) sometimes seen with; • leprosy (hands or feet) • spina bifida (feet only)

hand problems	• floppy paralysis (no spasticity)  **Figure** • 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.
	• uncontrolled muscle tightness (spasticity) • strange movements • or hand in tight fist  **Figure**	spastic cerebral palsy may lead to contractures
	burn scars and deformities	burns

	 Figure	
clubbing or bending of feet	may begin as floppy weakness and become stiff from contractures, if not prevented  Figure	may occur with many physical disabilities, including: • polio • cerebral palsy • spina bifida • muscular dystrophy • arthritis • spinal cord injury

DISABILITIES THAT OFTEN OCCUR WITH OR ARE SECONDARY TO OTHER DISABILITIES

IF THE CHILD HAS THIS	AND ALSO THIS	HE MAY HAVE
Developmental delay: child slow to learn to use her body or develop basic skills  Figure	caused by slow or incomplete brain function or by severe physical disability, or both	often seen in: • mental retardation • cerebral palsy • severely or multiply disabled children
	caused by overprotection: treating children like babies when they could do more for themselves	some delay can occur with almost any disability
Contractures	• usually due to muscle weakness or	often secondary to:

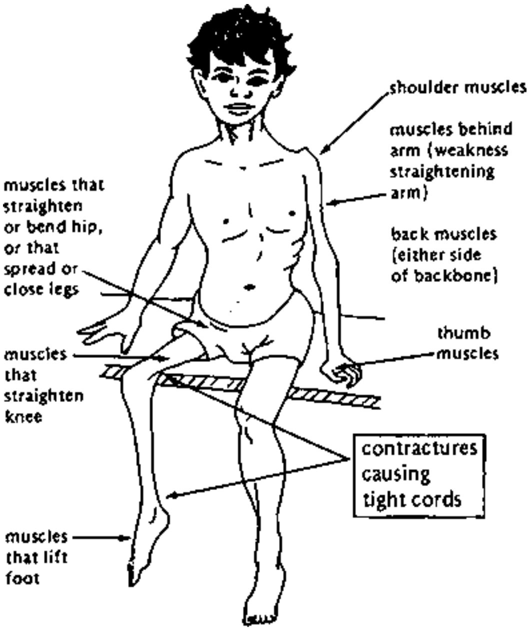
Contractures joints that no longer straighten because muscles have shortened  **Figure**	• usually due to muscle weakness or spasticity • Often, muscles that pull a joint one way are much weaker than those that pull it the other way (muscle imbalance).	often secondary to: • polio • cerebral palsy • spina bifida • arthritis • muscular dystrophy • Erb’s palsy • amputations • leprosy
	sometimes due to scarring from burns or injuries	burns
Behavior problems  **Figure**	may come from: • brain damage • difficulty understanding things • overprotection • 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
Slow to learn certain	• often over-active or nervous	learning disability

things only; otherwise intelligent.	• sometimes behavior problems	
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.  **Figure**	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.)
other problems that sometimes *occur **secondary*** to other disabilities (Some of these we have already included in this chart.)	**Main disability** • cerebral palsy	**Common secondary disabilities** • blindness • deafness • fits
	• many disabilities with paralysis	• spinal curve
	• persons who have lost feeling: leprosy, spinal cord injury, spina bifida	• pressure sores • osteomyelitis (bone infection) • loss of urine and

		bowel control

Chapter 7: Polio: Infantile Paralysis

HOW TO RECOGNIZE PARALYSIS CAUSED BY POLIO



MUSCLES COMMONLY WEAKENED BY POLIO

- ***Paralysis* (muscle weakness) usually begins when the child is small, often during an illness like a bad cold with fever and sometimes diarrhea.**

- **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.**

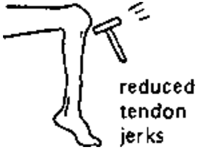
- **The muscles and bones of the affected limb become thinner than the other limb. The affected limb does not grow as fast, and so is shorter.**

- **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.) Also, the paralysis of polio is 'floppy'; limbs affected by cerebral palsy often are tense and resist when straightened or bent.**



Figure

- **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:

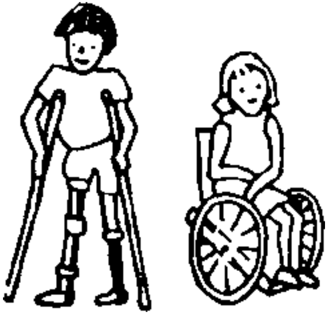
30% recover completely in the first weeks or months.

Figure

30% have mild paralysis.

Figure

30% have moderate or severe paralysis.



Figure

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

Figure

BASIC QUESTIONS AND ANSWERS ABOUT POLIO

How common is it? In many countries, polio - or ‘poliomyelitis’ - is still the most common cause of physical disability in children. In some areas, at least one of every 100 children may have some paralysis from polio. Where *vaccination* programs are effective, polio has been greatly reduced.

What causes it? A *virus (infection).* The infection attacks parts of the *spinal cord,* where it damages only the *nerves* that control movement. In areas with poor hygiene and lack of latrines, the polio infection spreads when the stool (shit) of a sick child reaches the mouth of a healthy child. Where sanitation is better, polio spreads mostly through coughing and sneezing.

Paralysis in one leg

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.

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.

Severe paralysis

At what age do children get polio? In areas with poor sanitation, polio most often attacks babies from 8 to 24 months old, but occasionally children up to age 4 or 5. As sanitation improves, polio tends to strike older children and even young adults.

Who does it most often affect? Boys, a little more than girls. Unvaccinated children much more often than vaccinated children. Young children who are given injections unnecessarily are paralyzed by polio more often those who are not.

How does the paralysis begin? It begins after signs of a cold and fever, sometimes with diarrhea 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? Often the paralysis will gradually go away, partly or completely. Any paralysis left after 7 months is usually permanent. The paralysis will not get worse. However, certain secondary problems may develop - especially if precautions are not taken to prevent them.

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.

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 further disabilities or complications that can appear after, and because of, the original disability.

CONTRACTURES OF JOINTS

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

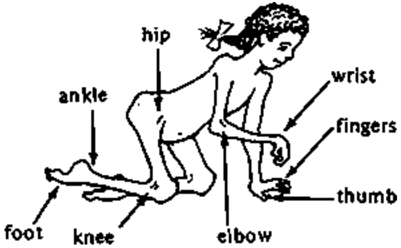
Unless preventive steps are taken, joint contractures will form in many paralyzed children. Once formed, often they must be corrected before braces can be fitted and walking is possible. Correction of advanced contractures, whether through exercises, casts, or

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 59.

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.



Figure

TYPICAL DEFORMITIES OF ANKLE AND FOOT

bending down at ankle (tiptoe contracture)

bending down at mid-foot

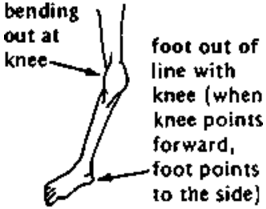
bending out at ankle

bending in at ankle

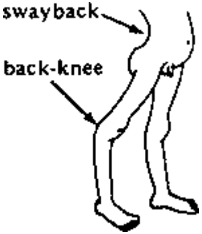
OTHER COMMON DEFORMITIES

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

OVER-STRETCHED JOINTS

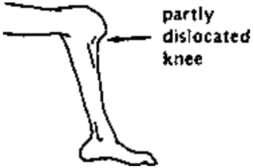


Figure



Figure

DISLOCATIONS



partly or completely dislocated joints (especially knee, foot, hip, shoulder, elbow, thumb)

partly dislocated foot

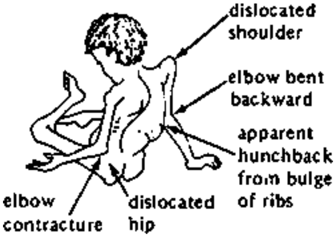
> ***WARNING:***
>
> **Dislocations** like these are sometimes caused by stretching contractures incorrectly.

SPINAL CURVE

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

Figure

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:

CEREBRAL PALSY

Polio has a more irregular pattern of paralysis:

POLIO

In cerebral palsy, usually you can find other signs of brain damage: over-active knee jerks and abnormal reflexes, 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.**

Figure

- **Hip problems 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.)**

Figure

- **Clubbed foot is present from birth.**

Figure

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

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

Figure

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

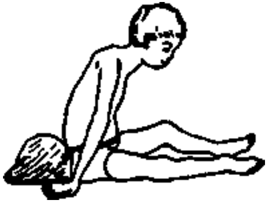
Figure

- **Spina bifida is present from birth. There is reduced feeling in the feet, and often a lump (or scar from surgery) on the back.**

Figure

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

- **Injuries to the spinal cord 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.**



Figure

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

Figure

- **Other causes of paralysis or muscle weakness. There are many causes of floppy paralysis similar to polio. One of the most common is 'Guillain-Barr' 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.**

- **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.**

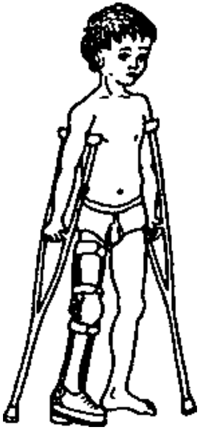
FOLLOWING THE ORIGINAL ILLNESS:

- **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 42. 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.**



Figure

- **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 or 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.

This child, who had polio as a baby, already had severe contractures in the hips, knees, and feet. (PROJIMO)

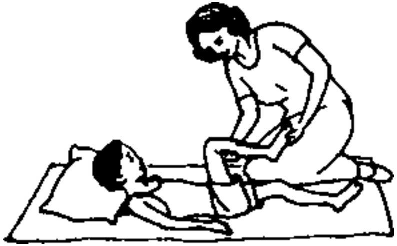
It took several months of exercises at home and then a series of plaster casts in the village rehabilitation center to straighten the contractures so he could walk with braces.

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.

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. And some aids or braces may prevent a child from developing strength to walk without aids. **Before deciding what aid or procedure to use, we suggest you read Chapter 56, "Making Sure Aids and Procedures Do More Good Than Harm."**

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

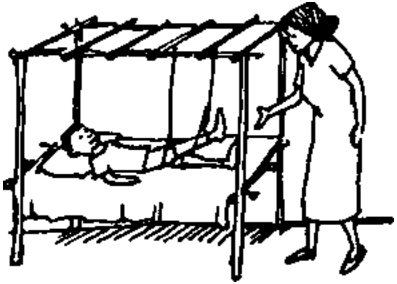


Figure

2. supported sitting in positions that help prevent contractures

Figure

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



Figure

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

Figure

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

Figure

Note: **These also provide good arm exercise in preparation for walking with crutches.**

6. braces to prevent contractures and prepare for walking

Figure

7. parallel bars for beginning to balance and walk

Figure

8. walking machine or ‘walker’

Figure

9. crutches modified as walker for balance and extra support

Figure

10. under arm crutches

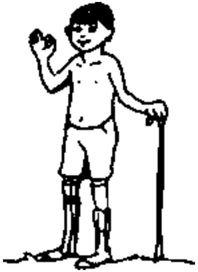
Figure

11. forearm crutches

Figure

and perhaps in time...

12. a cane or no arm supports at all



Figure

***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). 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?

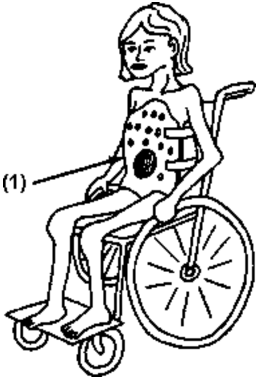
These early observations will help you know what parts of the body you most need to check for strength and range of motion. Often, by watching a child you can begin to get an idea about what kind of aids or assistance may help. For example:

Carmen 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.

Figure

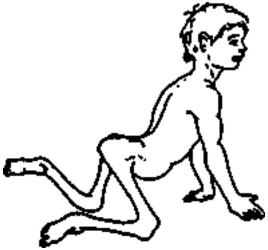
She will probably never walk, and will need a wheelchair or wheel board.



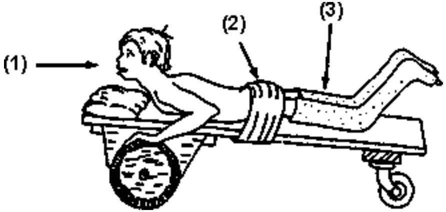
Figure

You may want also to make her a body brace (1), or help her in other ways to sit more upright and try to keep the spine from bending more.

Pedro 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.



Figure



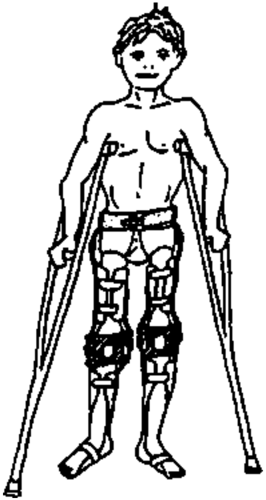
Figure

(1) Because his arms look strong, Pedro will probably be able to walk with crutches and leg braces. But first his contractures must be straightened.

(2) strap to gradually straighten hips

(3) casts to straighten knees and ankles

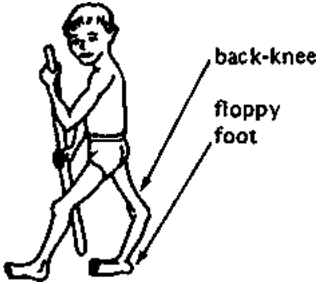
If the contractures cannot be straightened by gradual stretching, he may need surgery.



Figure

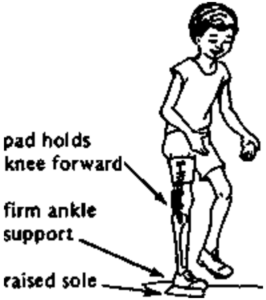
Because of hip weakness, he may need long leg braces with a hip band.

Manuel walks with the help of a stick. He appears to have paralysis mainly in his right leg and foot. Because of weak thigh muscles, he ‘locks’ his knee backward in order to bear weight on it. This ‘back-kneeing’ has become more and more extreme as the cords behind the knee stretch. The foot is very unstable and flops to one side. The weaker leg looks somewhat shorter - and for walking is much shorter because of the bent-back knee and bent-over foot.



Figure

He might be able to walk without the stick if he uses a below-knee brace to stabilize his foot.



Figure

But the back-knee would become worse and worse until he could not walk. So probably he should have a long-leg brace. The brace might allow his knee to bend backward just a little for stability - so that no knee lock is needed.

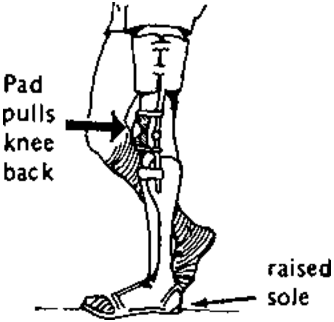
Afia leans forward and pushes her weak left thigh with her hand when she walks. Her left knee cannot quite straighten. Her weak leg looks a little shorter than the other.

Figure

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

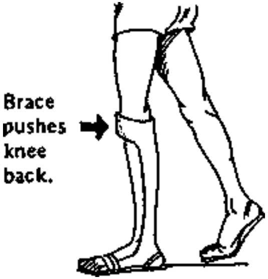
Figure

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



Figure

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



Figure

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 Afia, you will need to do a careful physical examination, testing range of motion and muscle strength of the hip, knee, and ankle joints.

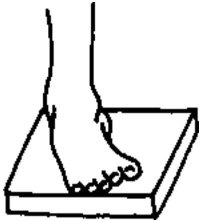
Step 2: This is the physical examination. It should usually include:

> **1. Range-of-motion testing, especially where you think there might be contractures. (See “Physical Examination”, and “Contractures”)**
>
> **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).**
>
> **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.**

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).

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.

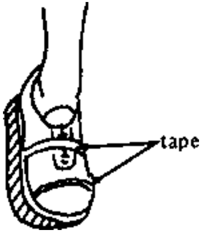
Step 5: Before making a final brace or aid to fit the child, if possible test to see how well it may work by using a temporary aid or old brace from another child. For example,



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.



Figure

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

Ask the child what she thinks.

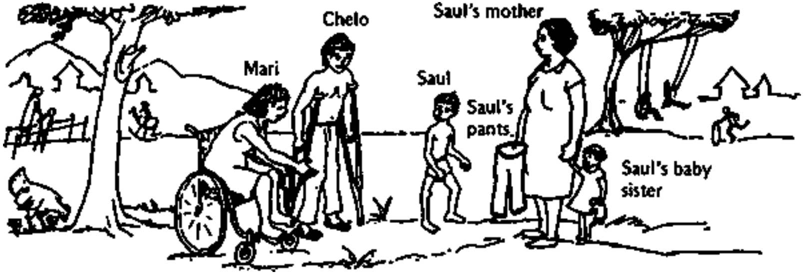
Step 6: After the child, her parents, and you have decided what kind of brace or aid might work best, take the necessary measurements and make the brace or aid. When making it, once again it is wise to put it together temporarily so that you can make adjustments before you rivet, glue, or nail it into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

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.

Mari and Chelo making a child's brace

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 SAUL



Figure

One day a mother from a neighboring village arrived at the village center with her 6 year old son, Saul. Mari and Chelo, 2 of the village rehabilitation workers, welcomed them warmly. Learning that Saul had polio as a baby, they asked him to walk, and then to run, while they watched carefully. Saul 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 Mari. “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 Chelo.

“Oh, please, no!” said Saul’s mother. “A year ago we took Saul to the city and the doctors had a big metal brace made for him. It cost so much we are still in debt! Saul 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.”

Figure

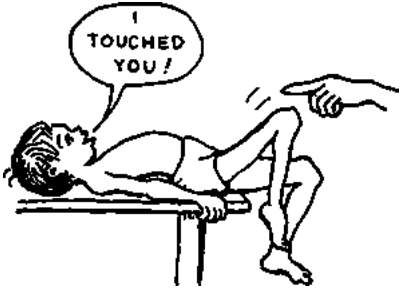
“That’s not surprising,” said Mari. “Often a child who can walk without a brace will refuse to use one - even if he walks better with it. We could make him a long-leg brace out of plastic. It would be much lighter. What do you say, Saul?” Saul began to cry.

“Don’t worry, Saul. Maybe we can do something simpler,” said Mari. “But first let’s examine you, okay?” Saul nodded.

On muscle testing Saul, 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,

Figure

and his hip forward,



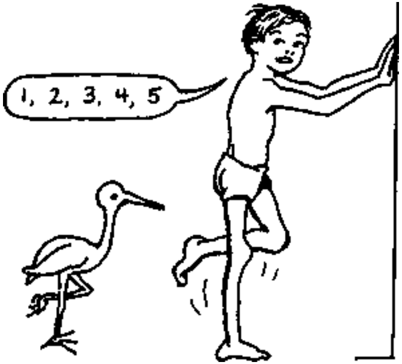
Figure

and good strength for bending his hip back,

Figure

“With the hip and thigh strength he has, he should almost be able to stand on that leg without the knee bending back,” said Mari. “Saul, let’s see you try it like this. Pretend you’re a stork!” For a moment Saul could do it. “Good!” said Mari. “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 Saul. “Sounds like fun!”



Figure

“The stork exercises may help,” said Chelo. “But I still think he needs a brace. At I east at first.”

“We must weigh the advantages against the disadvantages,” said Mari. “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 Saul 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.”

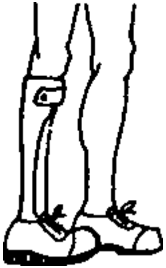
“Let’s try it!” Everyone agreed, except Saul.

short-leg plastic brace

Chelo brought someone’s old, lower-leg plastic brace and showed it to Saul. “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 Saul.

When the brace was made, they tested it. Saul 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.

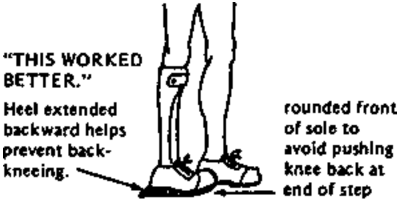


“WE THOUGHT IT WOULD WORK LIKE THIS…”

“BUT IN FACT IT WORKED LIKE THIS.”

“I have an idea,” said Chelo. “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.”

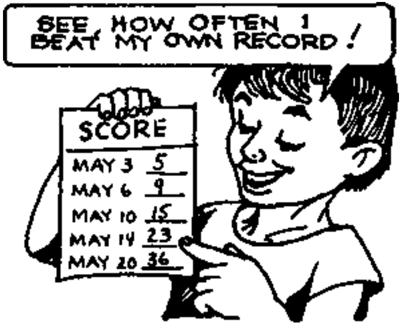
They tried it, and most of the time (especially when he was reminded) Saul walked without letting his knee bend back much.



Figure

At home Saul’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!

Figure



Figure

“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.

Figure

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:

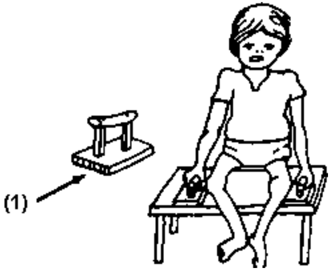
Have her try to lift her body weight off the ground with her arms, like this.

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.

Figure

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



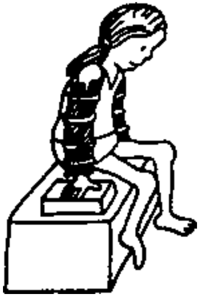
Figure

Having the child lift herself while holding a bar like this (1) will also help strengthen her hands and wrists for crutch use.

Figure

Pushing herself in a wheelchair or wheelboard (trolley) (2) 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.



Figure

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

Figure

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

Figure

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

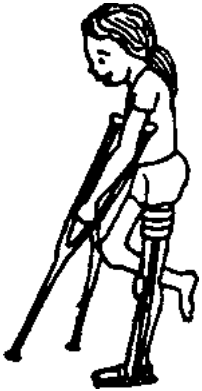
If the hips, knees, and feet can be placed in fairly straight positions, chances for walking soon with braces are good (if arm strength is good).

Figure

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.

Figure

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.



Figure

For correction of contractures, see Chapters 8 and 59.

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.

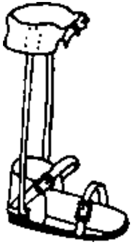
A child with a foot that hangs down (foot drop), or flops to one side may be helped by a below-knee brace of plastic or metal.

For foot drop, you can make a brace that lifts the foot with a spring or rubber band.

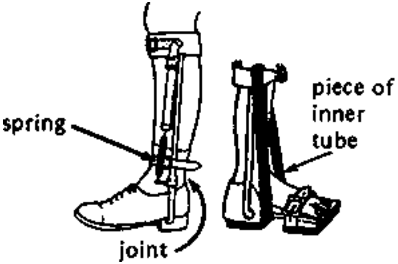
Foot drop: he cannot lift his foot.

Foot flops to one side.

PLASTIC



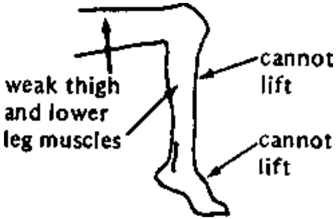
METAL



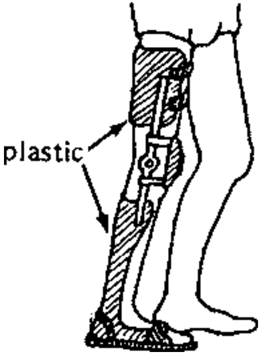
Figure

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 58.

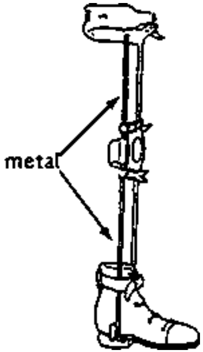
A child with a weak knee may need a long-leg brace of plastic or metal.



Figure



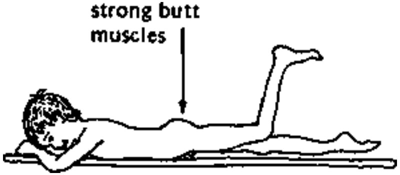
Figure



Figure

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 58.

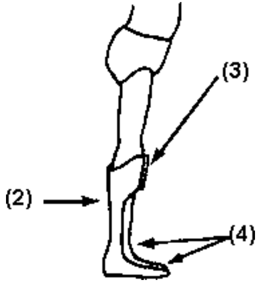
***Note:* Not all children with no strength to straighten the knee need long-leg braces: A child with strong butt muscles may be able to walk without a brace.**



Figure

Figure

STRONG butt muscles (1) pull the thigh back and keep the knee from bending.

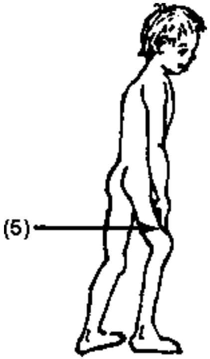


Figure

A child who has FAIR butt strength and a straight knee may be helped enough by a lower-leg brace (2) that pushes the knee back.

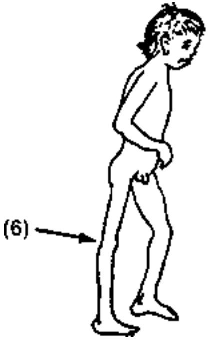
brace pushes knee back(3)

Slightly downward angle of a stiff brace causes it to push the knee backward when weight bearing (4).



Figure

A child with weak butt muscles may walk with one hand pushing on the weak thigh (5).



Figure

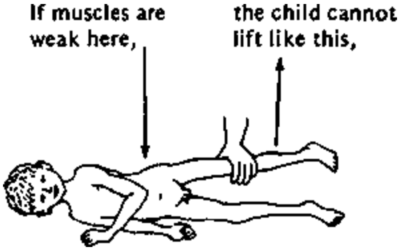
Or he may walk by bending the knee back to 'lock' it for weight bearing (6).

***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 56.)

Figure

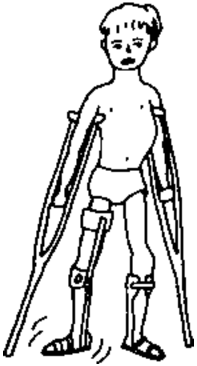
If a child has a contracture and cannot walk with his knee straight, correcting the contracture until his knee bends very slightly backward may allow him to walk better.

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



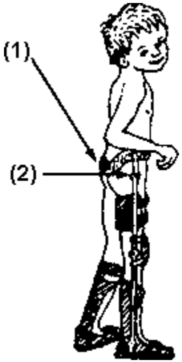
Figure

or if he cannot turn his leg in and out like this,



it may flop and twist with a brace like this.

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

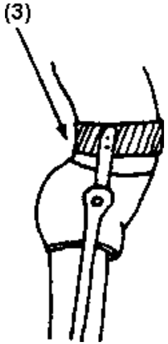


BETTER

A hip band that sits on the butt (1) often provides better posture than a higher waistband.

joint for sitting (with a lock if necessary) (2)

A plastic hip band is less stable but more flexible and allows better stepping in some children.

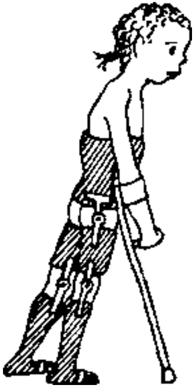


WORSE

A hip band that passes above the butt often lets the butt stick way out and causes swayback (3).

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.

If she has difficulty holding her body up like this,

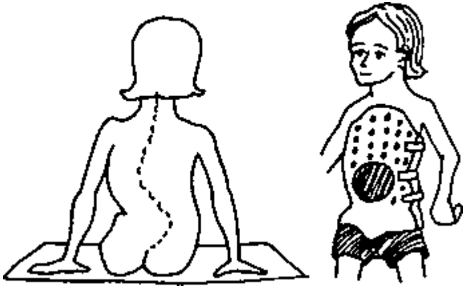


she may need a brace with body support.

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).



Figure

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 58.

PREVENTION OF POLIO

- **Vaccinate babies with polio vaccine. Be sure they get the vaccine 3 times by the time they are 8 months old. It is usually best to give the first polio vaccination around 3 months of age.**

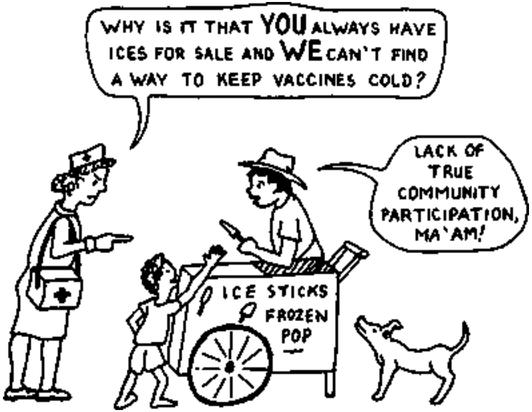
POLIO VACCINE, the best protection - IF it has been kept cold continuously!

Figure

- **Vaccinate as many children 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.**

- **Try to keep the live polio vaccine frozen until shortly before it is used. For up to 3 months it can be thawed and refrozen. 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.**



Figure

- **To give best protection, vaccinate the child when she does not have a fever or a cold or diarrhea. But if by 6 months of age, the child still 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.**

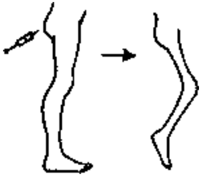
It is estimated that in poor countries at least one-third of vaccines are spoiled by the time they reach the children. Therefore, even in children who have been vaccinated, additional precautions are needed:

- **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.**

***DANGER*!**



Figure

INJECTIONS CAN CAUSE PARALYSIS FROM POLIO

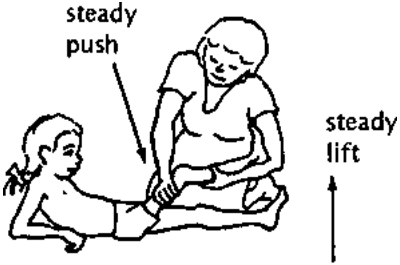
- **Organize the people and help out in popular campaigns to encourage vaccination, breast feeding, and limited, sensible use of injections. Community theater and puppet shows are good ways to raise awareness on these issues. See Chapter 48.**

PREVENTION of secondary problems

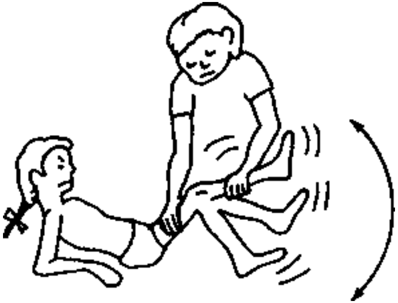
We have already discussed some ways to prevent new problems or complications in a child with paralysis. In summary, important measures include:

- **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, instead of 'pumping' the limb back and forth.



CORRECT



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.**

Figure

- **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 42

Crutch use, wheelchair transfers, etc., Chapter 43

Community needs, social adjustment, growing up, PART 2, especially Chapters 47, 48, 52, 53

Making sure aids and procedures meet the child’s needs, Chapter 56

* Braces and calipers, Chapter 58

* Correcting contractures, Chapter 59 Correcting club feet, Chapter 60

Special seating and wheelchairs. Chapters 64, 65, 66

* Aids for walking, Chapter 63

For more information on polio, see References.

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 the respect of the whole village. He has recently married a village woman.

Chapter 8: Contractures: Limbs That No Longer Straighten

WHAT ARE CONTRACTURES?

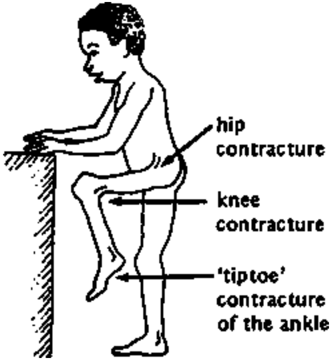
When an arm or leg is in a bent position for a long time, some of the muscles become shorter, so that the limb cannot fully straighten. Or shortened muscles may hold a joint straight, so it cannot bend. We say the joint has a 'contracture'. Contractures can develop in any joint of the body. For example:

1. **Miguel spent the first years of his life crawling because one leg was paralyzed.**

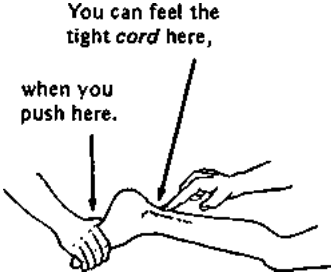
Figure

Because he could not stand, he kept his hip and knee bent and his foot in a tiptoe position, like this (1).

2. In time, he could not straighten his hip or knee, or bend his foot up. He had developed a:

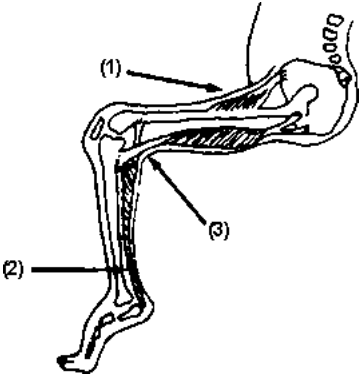


Figure



Figure

3. Because of the contractures, Miguel could not stand or walk, even with a brace.



Figure

shortened muscles causing hip contracture (1)

Shortened calf muscles cause a tight heel cord that keeps the foot in a ‘tiptoe’ position (2).

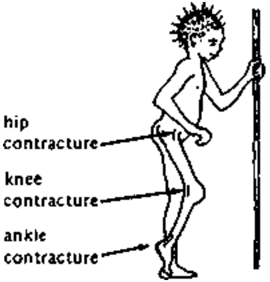
Shortened muscles-that-bend-the-knee cause tight cords behind the knee. This keeps it bent (3).

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.**

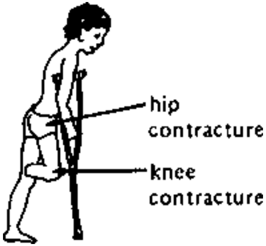
Figure

- **a paralyzed limb is kept bent or hanging.**



Figure

- **a child with an amputation keeps joints bent.**



Figure

- **a child has joint pain that prevents her from straightening her joints.**

Figure

contractures in:

- neck
- shoulders

- **back**
- **elbow**
- **wrists**
- **finger**
- **hips**
- **knees**
- **ankles**
- **feet**
- **toes**

Why is it important to know about 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.**

hand paralysis with 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.**

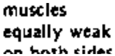
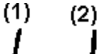
- **It is best not to let contractures develop, and if they do begin to develop, to correct them as soon as possible. Early contractures often can be easily corrected at home, with exercises and positioning. Advanced, old contractures are much more difficult to correct, and may require gradual stretching with plaster casts, or surgery.**

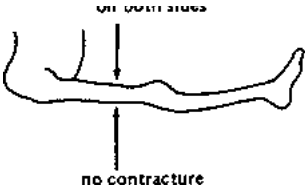
For all these reasons...

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.

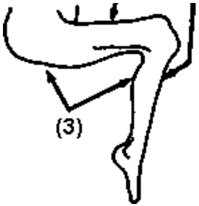
Muscle imbalance - a major cause of contractures

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 cause a muscle imbalance, contractures are much more likely to develop.

***WITHOUT* MUSCLE IMBALANCE-CONTRACTURES LESS LIKELY**	***WITH* MUSCLE IMBALANCE-CONTRACTURES MORE LIKELY**	
A leg that is completely paralyzed is not very likely to develop contractures. The knee may even straighten more than normal.	If the muscles that straighten the knee (1) and lift the foot (2) are very weak, and the muscles that bend the knee and lower the foot are strong,	Muscle imbalance causing contractures can result from spasms, or ***spasticity,*** that increase the pull of certain muscles (cerebral palsy and spinal cord injury).
		For example, the bent elbow and crossed legs of this child with spastic cerebral palsy can lead to contractures so that his legs cannot be spread apart



Figure



Figure

contractures are very likely to develop.

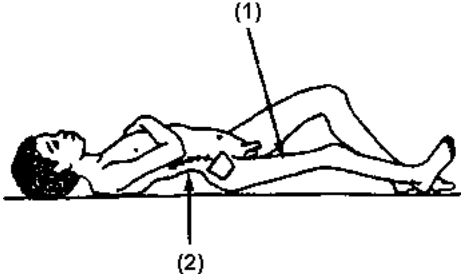
or his elbow straightened.

Figure

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)

EXAMINING THE CHILD FOR CONTRACTURES

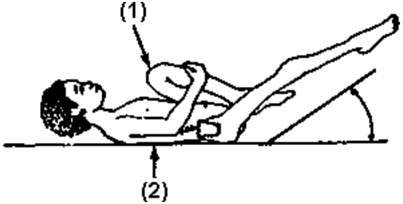
This is done through testing the 'range of motion' of different joints. Most contractures will be obvious when you test for them. But hip contractures can easily be missed.



Figure

(1) This child can lie with his right leg almost flat...

(2) ... by arching his back. You might think he has little or no hip contracture.

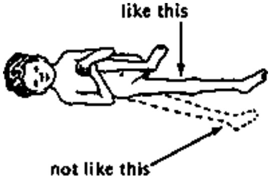


Figure

(1) But if you test him with his other knee bent up to his chest...

(2) ... his back flattens and you can see the amount of contracture.

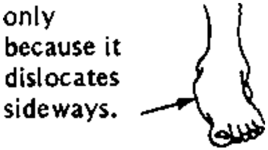
Be sure to test for contractures with the leg lined up straight.



Figure

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,



Figure

Figure

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

(CP) **Spasticity (muscle tightening that the child does not control) is common when there is damage to the brain or spinal cord. It is sometimes mistaken for contractures. It is important to know the difference.**

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.

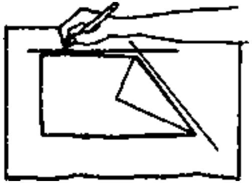
Spasticity often leads to contractures.

MEASURING CONTRACTURES

This can be done by folding a paper and measuring the angle, as shown here,

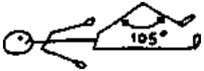
Figure

and then tracing that angle onto a record sheet.



Figure

You can record your measurements with stick figures.



Figure

Or an easier, more fun way is to use a flexikin.

Figure

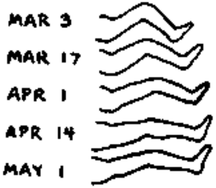
Or use a ‘compass’.

Figure

Or make a simple instrument of 2 thin pieces of wood joined by a bolt or rivet, tight enough so that they move stiffly.

Figure

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.



Figure

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.

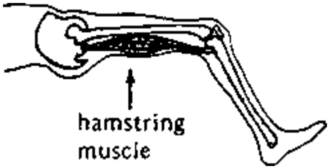
Note: If you find the information on this page hard to understand, do not worry. Come back to it later, when you meet very stubborn contractures.

TO TEST THE KNEE JOINT:

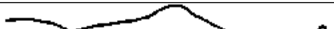
Check the range of motion of the knee with the hip straight and then bent.

Figure

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.



Figure

If the knee straightens more when the hip is straight	

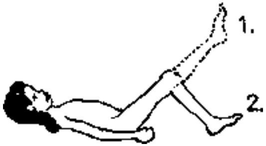
If the knee straightens more when the hip is straight	 **hip straight**
than when the hip is bent,	 **hip bent**
probably this is a **muscle contracture** (a short hamstring muscle).	
This can often be corrected in the village.	THE KNEE BENDS MORE: **MUSCLE CONTRACTURE**

But if the knee straightens equally when the hip is straight or bent,	 **Figure**
probably there is contracture of the **joint capsule.**	 **Figure**
This often requires surgery.	THE KNEE BENDS THE SAME: **JOINT CAPSULE**

	CONTRACTURE

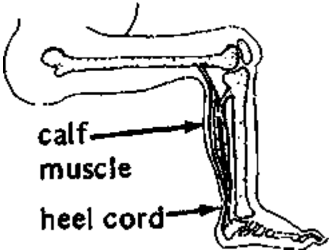
TO TEST THE ANKLE JOINT:

Check the range of motion of the ankle with the knee straight and then bent.

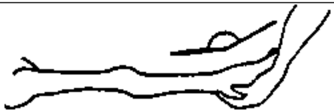


Figure

Explanation: One of the main muscles 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.



Figure

If the foot pushes down more when the knee is straight	 **knee straight**

than when the knee is bent, it is a **muscle contracture.**	 **knee bent**
This can often be corrected in the village.	THE FOOT BENDS UP MORE: **MUSCLE CONTRACTURE**

But if the foot angle is the same when the knee is straight or bent,	 **Figure**
there probably is a contracture of the **joint capsule.**	 **Figure**
This often requires surgery.	THE FOOT BENDS THE SAME: **JOINT CAPSULE CONTRACTURE**

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

(CP) Contractures can often be prevented by (1) positioning, and (2) range-of-motion exercises.

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, sitting, 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.

Figure

Lying and sleeping straight helps prevent contractures.

CORRECT

Figure

Also use pillows for side-lying to keep a good position.

WRONG

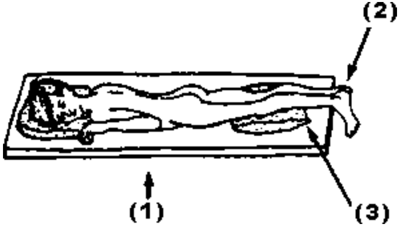
Figure

Lying and sleeping with t
legs in a twisted or bent

(1) Lying part of the time face down helps stretch hips backward.

(2) Letting feet hang over edge helps prevent ankle contractures.

(3) A pillow here helps stretch knees.



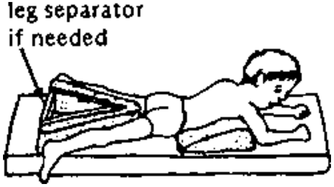
Figure

Support feet at right angles.

If knee contractures might develop, keep the knees straight as much as possible.

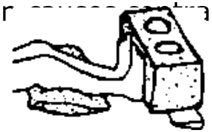
Figure

A foot board helps to prevent ankle contractures.



Figure

position causes contractu



Figure

The foot support can be leaned forward a little So that the child can stretch feet by pushing against it (Be sure to pad it.)

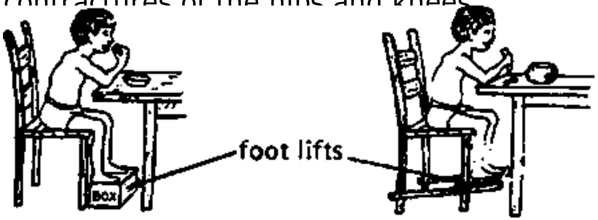
Figure

A child who spends most of the time sitting should spend part of the c
lying or standing (on a frame if necessary). This will help prevent contractures of the hips and knees.

WRONG

Figure

BETTER



Figure

BEST

child-sized furniture

Figure out ways to help the child stay in contracture-preventing positions.

For a child with spasticity whose legs press together or cross, look for ways to sit, lie, or carry him with legs separated. Here are a few examples.

Figure

For more ideas about special seating and positioning, see Chapter 65.

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.

Figure

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 42.

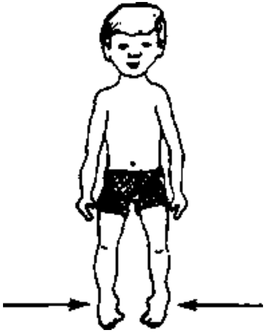
As much as possible, the child herself should try to move the affected part through its range of motion. Often the limb will be too weak and help is needed. But be sure the child moves it as much as she can herself.

Figure

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.

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 outward, like this.

Walking on boards in a V-shape may provide similar stretching and be more fun.

Figure

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.

Figure

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

Figure

1. Someone else moves the limb. Often necessary - but not much fun.

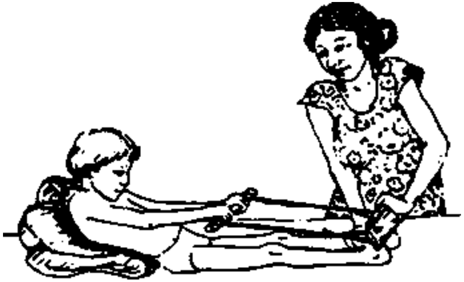
Figure

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.)

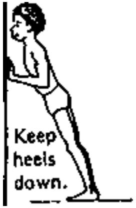
Figure

Here the child does his own stretching with some help from his mother.



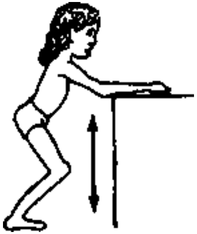
Figure

Leaning against a wall stretches the feet more than standing upright does.



Figure

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.



Figure

Figure

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.

Figure

3. The child does the exercise-using muscles of the affected part.

WITH ASSISTANCE:

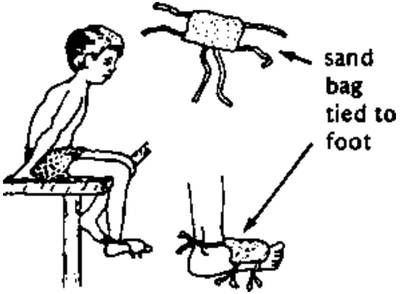
If the child has some strength to raise his foot, have him raise it as far as he can. Then help him to raise it as far as it will stretch.

Developing the muscles that lift the foot may help prevent contracture.

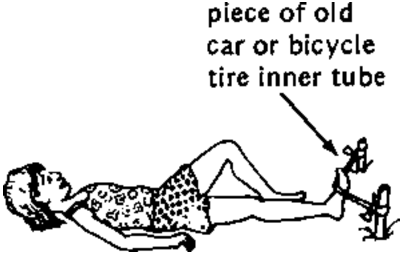
Figure

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.**



Figure



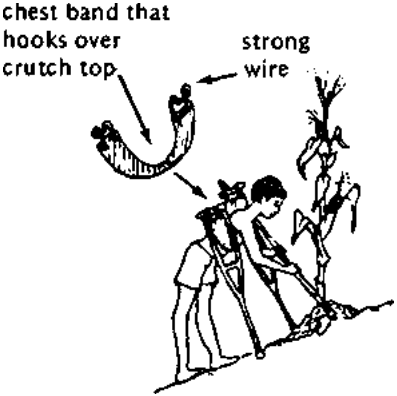
Figure

4. The child does the exercise - during normal daily activities.

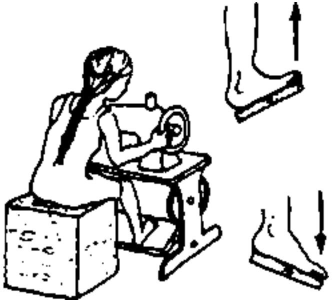
Figure out ways or aids so that the child can take part in ordinary activities that stretch muscles and prevent contractures.

standing and walking uphill to stretch heel cords

picking vegetables



Figure



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:

Figure

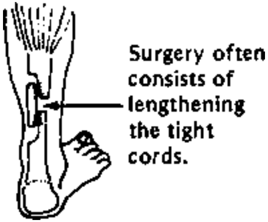
First, correct it as far as you can with stretching exercises and positioning.

Figure

Second, correct it as much as possible with a series of casts or special braces.

Figure

Third, if more correction is still needed, consider surgery.



Figure

Instructions for correcting contractures using plaster casts or braces are in Chapter 59.

***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 42 and 56). 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 or 10 minutes. Repeat several times a day.**

Figure

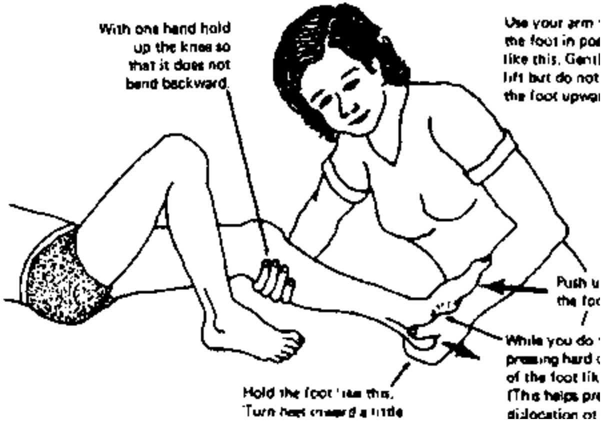
CAUTION: **To avoid damaging the limb, hold it near the joint**, as shown. It is acceptable if the stretching hurts the child a little, but it should not hurt him a lot. **If you want faster results, do not apply more force. Stretch the limb for longer and more times each day.**

In children who do not feel in their legs, take special care not to stretch forcefully. You could cause injuries.

STRETCHING EXERCISE INSTRUCTION SHEETS

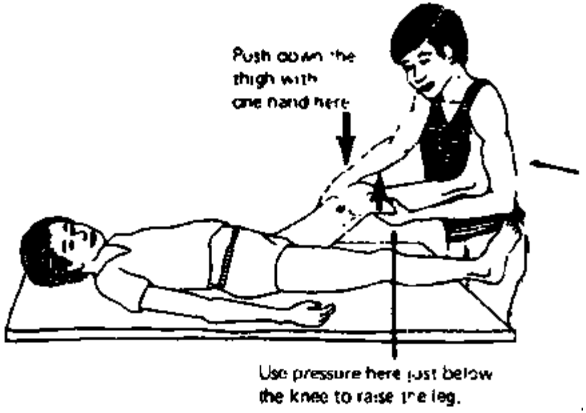
Some stretching exercises are done best using special techniques. Often they need to be done at home for weeks or months. You will find instruction sheets for the most frequently needed stretching exercises in Chapter 42, “Range-of-motion and Other Exercises.” They include:

Stretching exercise for a tight heel cord.



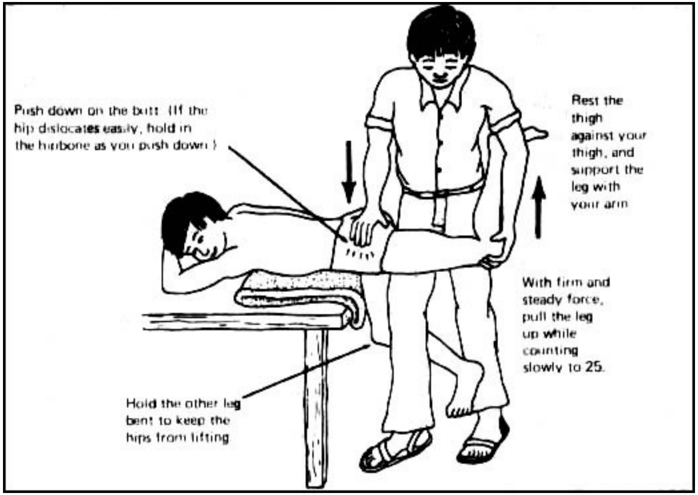
Figure

Stretching exercise for a bent knee.



Figure

Stretching exercise for a bent hip.



Figure

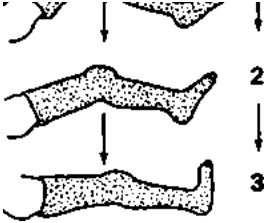
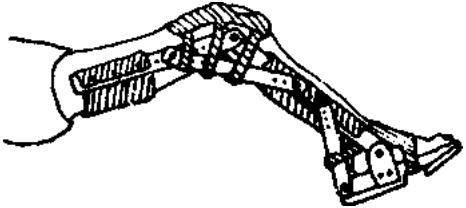
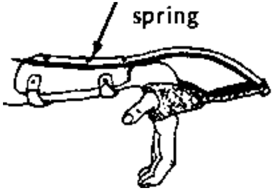
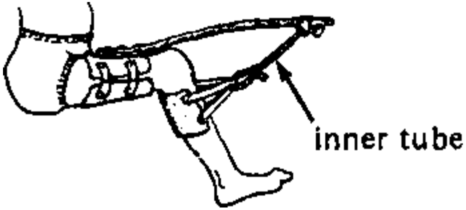
HOLDING A CONTRACTED JOINT IN A STRETCHED POSITION FOR LONG PERIODS

Chapter 59 discusses the use of casts, braces, and other aids to stretch difficult contractures. These include:

a series of plaster casts and wedges

adjustable braces

elastic stretching devices

 Figure	 of metal and plastic  of wood	 Figure  Figure
Advantages:	**Advantages:**	**Advantages:**
• Holds leg in exactly the position you want it. • Child (or parents) cannot easily remove it. • Especially useful for difficult deformities that bend in different directions.	• Can be adjusted by family at home. • Can be easily removed to check for sores, for bathing, and exercise.	• Same as for adjustable braces, and also: • Does not need frequent adjustment because it keeps pulling as joint stretches.
Disadvantages:	**Disadvantages:**	**Disadvantages:**
• Cannot be easily removed to check for sores, to bathe, and to exercise. (Therefore, casts	• More difficult to make and to fit well.	• Clumsy - gets in the way. • Difficult to make so they work

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.	• Difficult to use on child with various deformities that go in different directions. • Child (or parents) may remove and not use it.	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.**

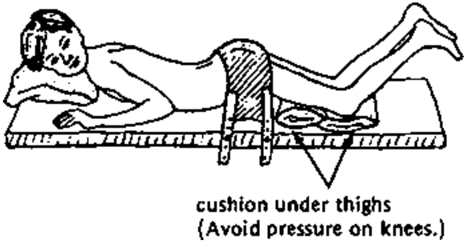
Figure

Less advanced hip contractures like this can sometimes be straightened using **positioning and**

straps.

Figure

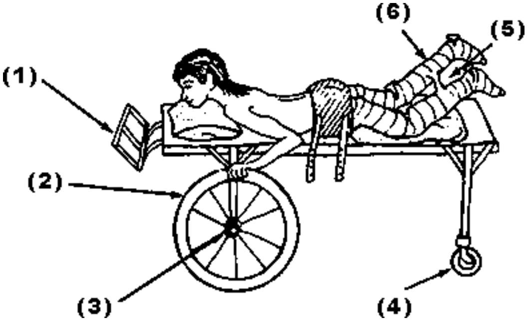
The child lies face down with a wide strap pulling his butt down.



Figure

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.



Figure

(1) A rack bookholder so she can play or read.

(2) large bicycle wheels

(3) extra strong axles and hubs

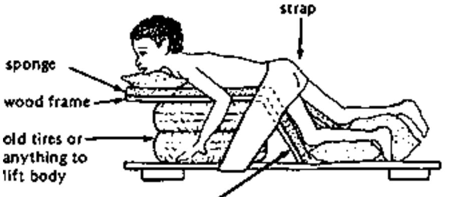
(4) 'caster' rear wheels, for turns

(5) 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).

(6) casts to straighten knees and ankles

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.

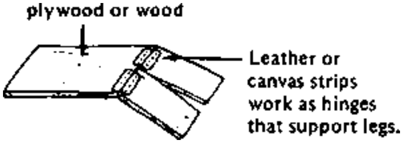
The child with more severe contractures at the hips may need to be strapped on an angled frame.



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.

Figure

For children with different angles of contracture in each hip, the 2 leg boards can be adjusted differently.



Figure

For additional information on contractures relating to different disabilities, aids, and equipment, see the INDEX under 'Contractures'. For methods to correct contractures, see Chapter 59.

Chapter 9: Cerebral Palsy

WHAT IS CEREBRAL PALSY?

Cerebral palsy means 'brain *paralysis'*. It is a *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.**

NORMAL

Child hangs in upside down 'U' with little or no movement.

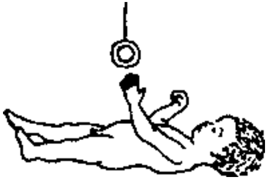
FLOPPY

- **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.**

Figure

- **He may not use his hands. Or he only uses one hand and does not begin to use both.**



Figure

- **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.**

Figure

- **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.

Figure

- **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 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.

Figure

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.

Even if a child can hear loud banging, he may not hear well enough to understand words.

Figure

• 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 40.)

• 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.**

TYPES OF CEREBRAL PALSY

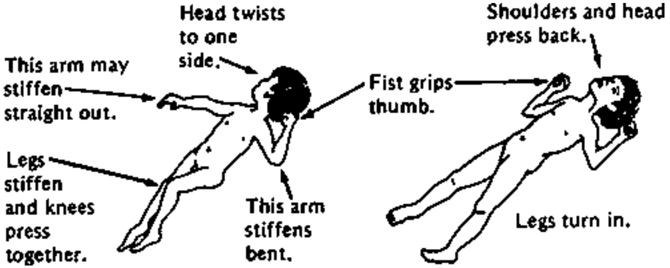
Cerebral palsy is different in every child. Different experts have worked out different ways of describing it. But do not worry about labeling a child’s particular type of cerebral palsy. This does not usually help his treatment.

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:



Figure

Stiffness, with the knees bent or with legs separated, occurs more commonly in the child with spasticity and athetosis combined (see below).

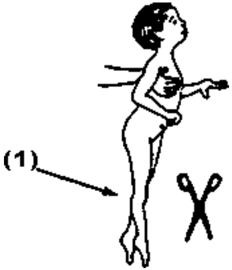
Figure

Less commonly the head and shoulders may stiffen forward...

Figure

... or the arms may stiffen straight across the body, with the head pressed back.

Figure



Figure

When you try to stand the child the legs often stiffen or cross like scissors (1).

Figure

The child who learns to walk may do so in a stiff, awkward position, with the knees pulled together and bent (1). Feet often turn in.

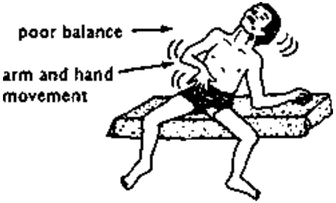
2. UNCONTROLLED MOVEMENTS OR ‘ATHETOSIS’

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.

Figure



This child has severe athetosis.

3. POOR BALANCE OR 'ATAXIA'

The child who has ‘ataxia’, or poor balance, has difficulty 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).

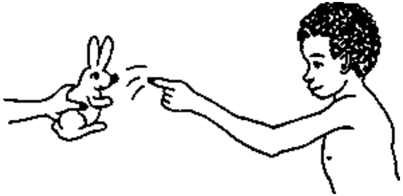
Because children who have mainly a balance problem often appear more clumsy than disabled, other children are sometimes cruel and make fun of them.

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.

Figure

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.



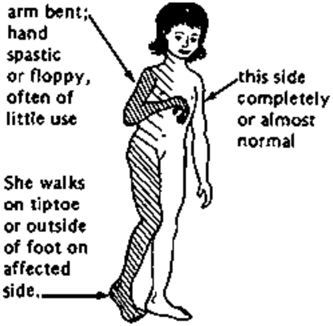
Figure

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.

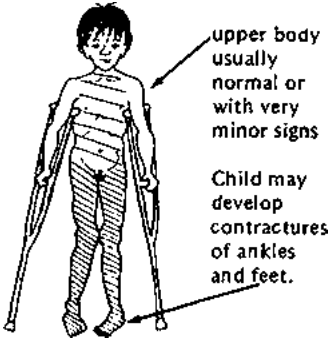
***NOTE**: Children with any type of cerebral palsy as **babies are often mainly limp or floppy.** Stiffness or uncontrolled movements begin little by little. Or the child may be limp in some positions and stiff in others.

Parts of the body affected

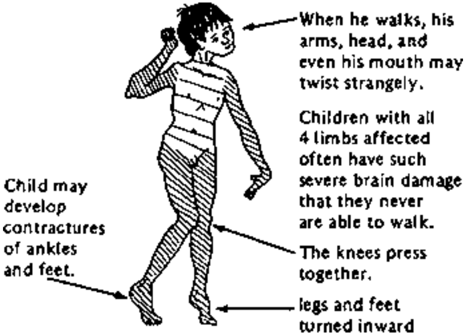
DEPENDING ON WHICH LIMBS ARE INVOLVED, THERE ARE 3 TYPICAL PATTERNS:



ARM AND LEG ON ONE SIDE (HEMIPLEGIC)



BOTH LEGS ONLY (PARAPLEGIC) or with slight involvement elsewhere (DIPLEGIC)



BOTH ARMS AND BOTH LEGS (QUADRIPLEGIC)

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:**
  - **Infections of the mother while she is pregnant. These include German measles and shingles (herpes zoster).**
  - **Differences between the blood of mother and child (Rh incompatibility).**
  - **Problems of the mother, such as diabetes or toxemia of pregnancy.**
  - **Inherited. This is rare, but there is a 'familial spastic paraplegia'.**
  - **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.**

- **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.**

  - **Brain infections *(meningitis, encephalitis)*. There are many causes, including malaria and tuberculosis.**

  - **Head injuries.**

  - **Lack of oxygen from drowning, gas poisoning, or 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 cause.**

  - **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. Can persons with cerebral palsy marry and have children? Yes. And the children will not have the condition (except maybe in a very rare type of cerebral palsy).

4. 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. However, surgery to weaken or release spastic muscles is less often effective and sometimes makes things worse. Careful evaluation is needed. Surgery usually should be considered only if the child is already walking and has increasing difficulty because of contractures. In a child who cannot balance well enough to stand, surgery usually will not help. Sometimes surgery to separate the legs can help make cleaning and bathing easier.

5. 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.

***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.

Figure

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.

6. 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. **Self-care activities such as eating, dressing, toileting**
4. **Getting from place to place**
5. **(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.

Most 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.

The legs stiffen and the feet go into a rigid tiptoe position.

This child is ***not*** almost ready to walk.

Figure

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.

In a Mexican village, we know 2 brothers, both with cerebral palsy.

Petronio walks but with great difficulty. Walking tires him and makes him feel so awkward that he stays at home and does not play or work. He is unhappy.

Figure

His brother, Luis, cannot walk. But since he was small, he has loved to ride a donkey. He uses a wall to get off and on by himself. He goes long distances and earns money carrying water. He is happy.

Figure

(Not only does the donkey take Luis where he wants to go, but by keeping his legs apart, it helps prevent knock-knee contractures. This way '*therapy*' is built into daily activity.)

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).

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? sit? 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:

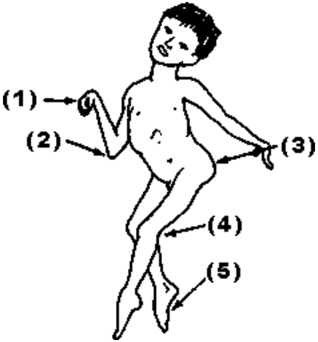
Figure

Figure

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 of Maricela on pages 5 to 7 and the story of Enrique.

HELPING THE CHILD ACHIEVE BETTER POSITIONS

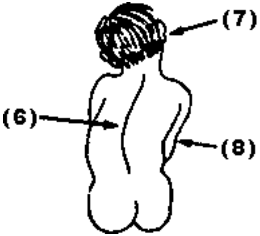
Due to abnormal pull of muscles, children with cerebral palsy often spend a lot of time in abnormal positions. These abnormal positions of the limbs and body should be avoided as much as possible, or the child can become deformed. For example,



Figure

A wrist (1) or elbow (2) that is always bent can lead to contractures (muscle shortening) that make it impossible to straighten the arm or hand.

Hips (3) that are continually bent forward, or to one side, or knees (4) that are always held together, or never completely straightened, or feet (5) 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.



Figure

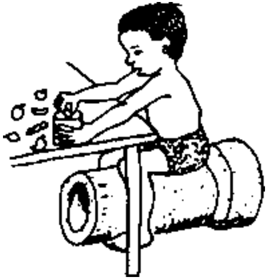
A twisted position can lead to curvature of the *spine* and tilting of the hips (6).

If the head is always turned or bent to one side (7), in time the neck may become permanently twisted.

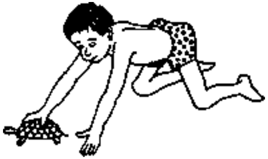
An arm that is held tightly to the side will in time become difficult to raise away from the side (8).

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.**



sitting



crawling

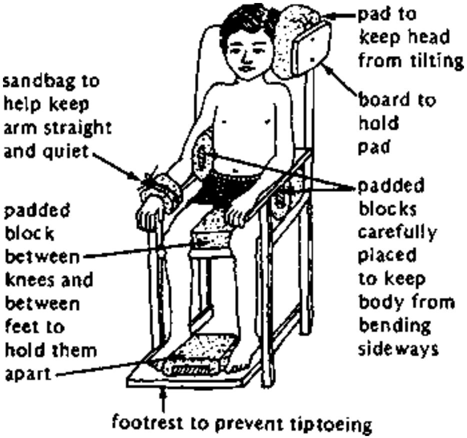
lying

standing

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 at the top of the page might need a chair like this.



Figure

***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 that 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,

Figure

encourage her to reach out and hold objects.

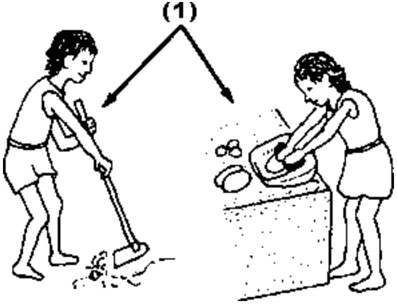
Figure

Or she may need a post to hold on to.

Figure

If she bends backward a lot,

Figure



Figure

she needs actions that bend her head, body, and shoulders forward, like these (1).

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.

Figure

The baby's legs can be held apart by using many thicknesses of diapers *(nappies)* like this,

Figure

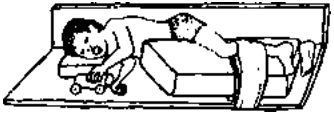
or by pinning her legs like this (when sleeping).

Figure

If the child's body often arches backward,

Figure

try positioning him to lie and play on his side.



Figure

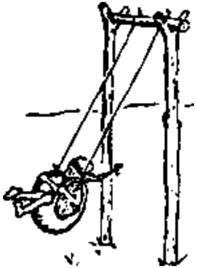
Look for ways to break the spasticity by bending him forward,

Figure

or over a barrel (or beach ball or big rock, etc.),

Figure

or in a car tire swing.

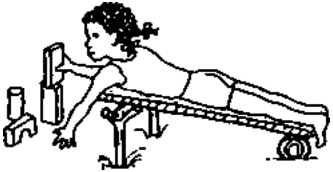


Figure

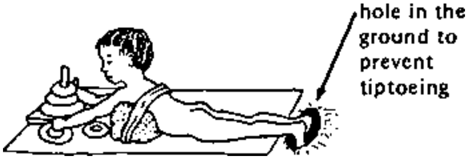
If the child does not have enough control to reach out in this position,

Figure

help position him so he can lift his head using his arms.



Figure



Figure

If the child’s head always turns to the same side,

Figure

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

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.

Figure

Then help her learn to twist her body and roll.

Figure

Figure out games so that the child *wants* to twist, and does it without help.

Figure

Figure

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,

Figure

sit him with his legs apart and turned outward.

Also lift his shoulders up and turn his arms out.

Figure

Look for simple ways to help him stay and play in the improved position without your help.

Figure

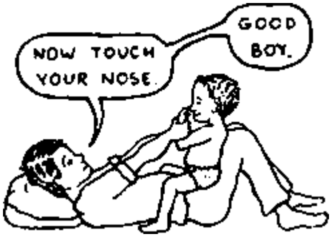
Sitting with the legs in a ring helps turn hips outward.

Figure

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.

Figure

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!



Figure

As the child develops, encourage her to put her arms and body in more normal positions through play and *imitation.*

Figure

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.

Figure

Sitting in a "W" should usually be discouraged because it can increase contractures and

loosen or damage hips and knees. However, if it is the only way a child can sit and use her hands, it should be allowed.

Figure

Look for ways for the child to sit with legs spread forward. Here are 2 examples.

The pot or log keeps the knees apart. The holes for heels help too.

Figure

Figure

If the child’s legs stay apart, his butt sticks out, and his shoulders are pulled back,

Figure

first sit him with his body bent forward and his legs together. Then bend his shoulders forward and turn them in.

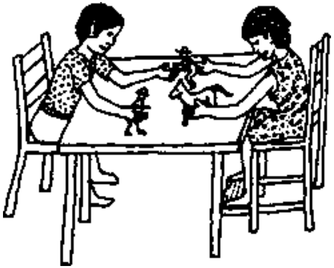
Figure

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)

Figure

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.



Figure

Be sure her feet are on a flat surface.

Figure

For ideas on special seats and sitting positions to prevent 'knock-knee' contractures, see below.

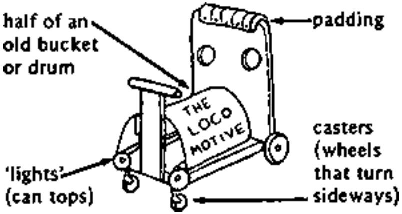
Moving about

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

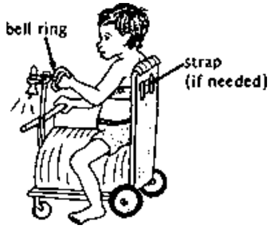
craftspersons.

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.

Figure



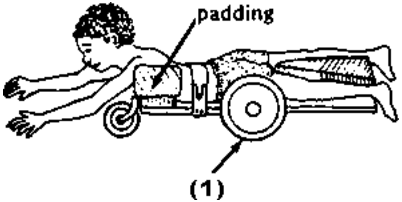
Figure



Figure

Wheel boards

Adapting wheel boards for travel on rough surfaces

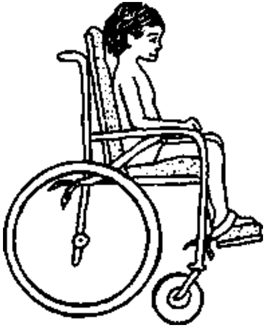


Figure

By placing large wheels (1) 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.

Some children will need wheelchairs. For wheelchair designs, see Chapters 64, 65 and 66.

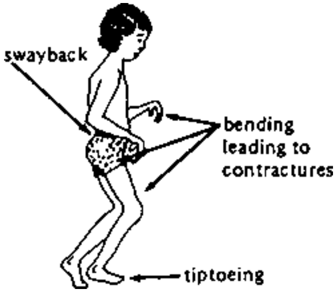


Figure

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.



Figure

When you help the child keep her balance, she is less tense and can stand straighter.

Figure

Look for ways to provide similar assistance during play and other activities.

Here a cart provides easier balance and keeps the arms straight.

Figure

Miguelito 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.

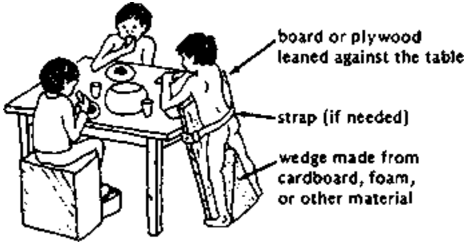
Two sticks can help the child once she develops some standing balance. At first you can hold the tops of the sticks. But let go as soon as possible.

Figure

CAUTION: Be sure sticks are taller than child so that she will not injure herself if she falls.

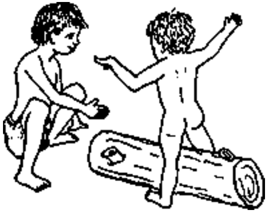
CAUTION: Be sure sticks are taller than child so that she will not injure herself if she falls.

The child who cannot yet stand alone can be placed in a standing frame for an hour or 2 each day.



Figure

Figure



Figure

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.

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 center of the Khao-i-dang refugee camp in Thailand develops hand control by sliding colored rings on a pole.

Figure

A boy with cerebral palsy at the PROJIMO rehabilitation center helps paint a chair frame.

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,

Figure

do not carry him like this.

Carry him in ways that straighten his arms and bend his knees and hips.

Figure

As the child gains more control, you can carry him with less support.

Figure

The child with spasticity who is usually curled up,

Figure

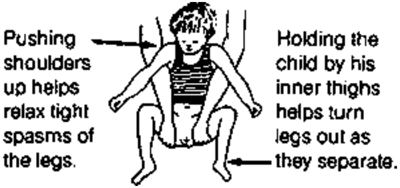
can be carried like this.

Figure

The child with severe spasticity who tends to straighten and arch backward can be carried like this.

Figure

For play, you can swing the child in the air in this position.



Figure

While working, you can carry the baby with legs spread across your hips or back, as is the custom in many places.

Figure

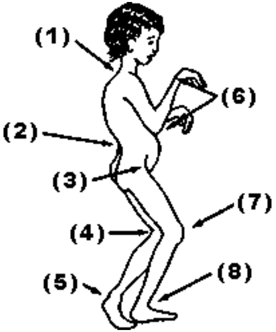
CONTRACTURES IN CEREBRAL PALSY

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 CONTRACTURE
(Uncontrolled tightening of muscles) → (Fixed shortening of muscles)

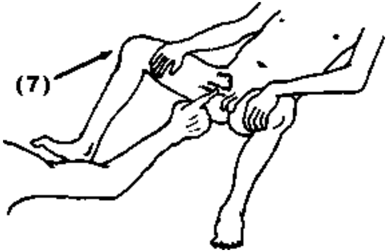
The typical contractures of cerebral palsy are similar to the abnormal positions of cerebral palsy. They can include:



Figure

(1) neck contractures that pull the head back or to one side
(2) sway back
(3) bent-hip contracture
(4) bent-knee contracture
(5) 'tiptoe' contracture
(6) An arm and hand that are always bent may cause contracture of elbow and wrist.
(7) 'knock-knees' contracture
(8) Ankle and toot contractures may bend IN, DOWN, UP or OUT depending on the spasticity.

Stretching the knees apart you can see and feel the very tight cord in the groin.



Figure

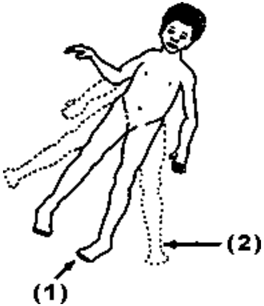
Chapter 8 discusses contractures, and ways to prevent and correct them. Page 79 explains how to tell spasticity from contractures.

Spasticity and contractures combined

Decreased range of motion may be caused partly by spasticity and partly by contractures. Therefore, whenever a child has spasticity, check to see if contractures are also forming, and if so, how much.

This girl with cerebral palsy has spastic muscles that hold her knees tightly together.

Figure

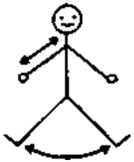


Figure

When she is helped to relax and her legs are slowly separated, they will only open this far (1).

Normally her legs should open this far (2). This means she has contractures on the inner side of her thighs (groin).

One way to record spasticity and contractures:

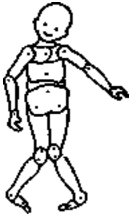


Normal

With Contracture

With Spasms

You can use a flexikin to record the positions.



Figure

PREVENTING CONTRACTURES

In cerebral palsy, it is important that steps to prevent contractures be included in activities that help the total development 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 8, “Contractures,” and in Chapter 42, “Range-of-Motion and Other Exercises,” 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:

1. **Apply warm soaks to spastic muscles or have the child sit or lie in warm water.**

Figure

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.

Figure

CAUTION

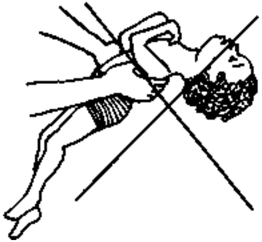
ABOUT MASSAGE

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 whole 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.

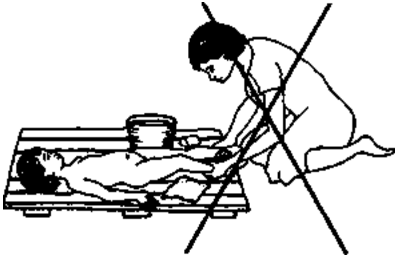
RIGHT

Whatever you do with the child, look for ways that will help relax and stretch the tight muscles. Here are some examples.

Rosa’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

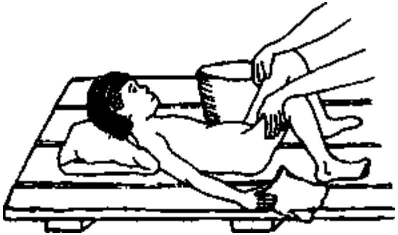


WRONG

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



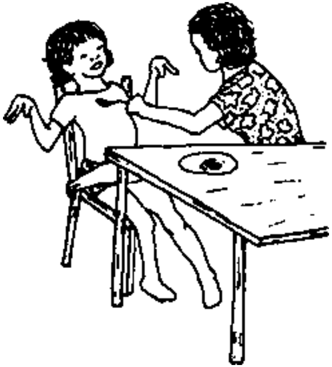
Figure

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.

Figure

When you try to feed the child, if her head and shoulders stiffen backward,



Figure

do not **try to pull her head forward. It will push back more.**

WRONG

You may find that her head relaxes more if you put your arm across the back of her neck and push her shoulders forward.

Figure

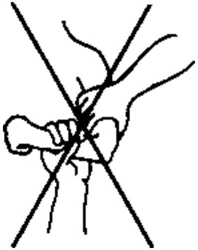
Or, you may find that raising the front of the chair seat keeps her hips bent, relaxes her in general, and gives her much more control.

Figure

When you want to help your child dress, if her arms press against her chest,

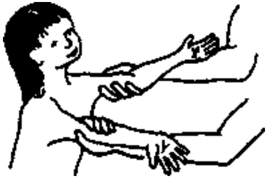
Figure

do *not* try to pull them straight. They will stiffen more.



WRONG

Try holding her arms above her elbows, and gently turning her arms out and straighten them at the same time.



Figure

***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 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 34 and 35 are about **helping the child whose mind and/or body are slow to develop.** Chapters 36 to 41 discuss ways of **helping children develop and become more self-reliant.**
>
> Although Chapters 34 to 41 are written 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 292 and 293. 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 become 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.

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 35, "Early Stimulation Activities," especially pages 306 to 312. 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,

Figure

and reaching sideways.

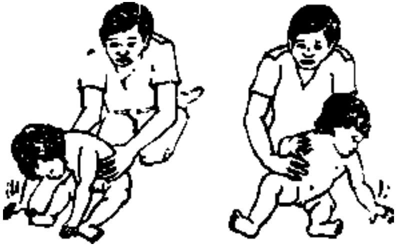
Figure

Lie him on your body and tip a little from side to side so that he begins to catch himself.

Figure

When sitting

Let her start to fall so that she begins to catch herself.



Figure

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.

Figure

Encourage the child to twist and reach to the side.

Figure

Use as little sitting support as needed. Often low back support is enough for a child who straightens stiffly

Figure

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

Figure

Figure

Shift weight from one leg to the other.

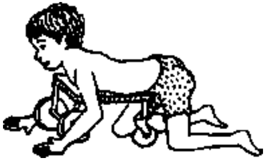
Figure

Play trying to balance on a tipping surface.

Figure

Crawl forward, sideways, and backward.

Figure



crawling scooter

For standing and walking

Stand and balance on knees.

Figure

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.

Figure

Help with standing and then walking.

Figure

Give less and less support while he walks with only a ‘safety-belt’-and then alone.

Figure

Have the child practice stepping forward, backward, and sideways.

Figure

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.

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)

Figure

Help the child become as independent as possible in eating, dressing, washing, toileting, and in meeting other daily needs. Do this by guided practice, imitation, and step-by-step learning. These self-care skills are discussed in Chapters 36 to 39.

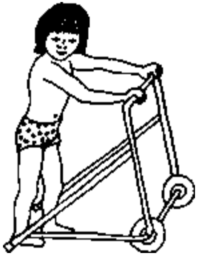
Develop some form of moving about and, if necessary, use wheel-boards, wheelchairs, pedal tricycles, walkers, crutches, or other aids. (See Chapters 63, 64, 65, and 66.)

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.

Figure

She does much better on a higher walker with a handgrip that runs from one side to the other.



Figure

Often leg braces *do not* help a child with cerebral palsy walk better. But sometimes they do. When in doubt, try low-cost braces first, to look for possible problems. For example:

Carla walks in a very crouched position.

Figure

She may be helped by below-knee braces that hold her feet at nearly a right angle (90°)

Figure

or by above-knee braces that keep her knees almost straight...

Figure

But it is possible that the below-knee braces will throw her badly off balance,

Figure

and that the above-knee braces will make balancing even harder.

You will need to experiment!

Figure

Even if braces for walking do not work, Carla may be helped to walk straighter by using 'night splints' to hold her knees straight and prevent contractures.

> ***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 for treating or teaching her.

> ***CAUTION****:* Many suggestions for developing basic skills are discussed in Chapter 34, "Child Development and Developmental Delay," and Chapters 36 through 39 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 muscle 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.**

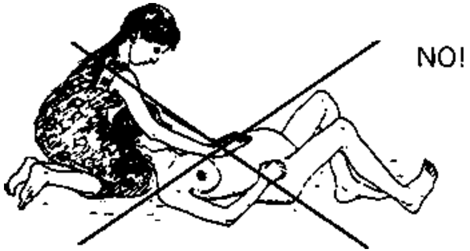
- **If possible, girls should avoid pregnancy until full grown (16 or 17 years old).**

- **Avoid unnecessary medicines during pregnancy.**

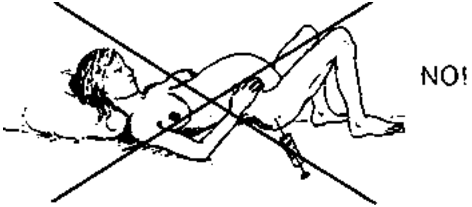
- **Try to avoid getting near persons with German measles during pregnancy. Or get vaccinated against German measles before becoming pregnant.**

- **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. 256.)**

- **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, pituitrin, 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. 262.)**

- **Breast feed the baby (breast milk helps prevent and fight infection), and make sure the baby gets enough to eat. (See *Where There Is No Doctor,* p. 121 and 271.)**

- **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.

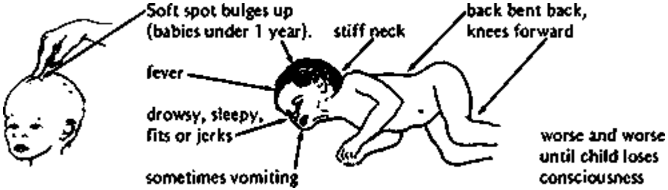
Never wrap the baby up in clothing or blankets.

Figure

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 on pages 75 to 76 of *Where There Is No Doctor.*

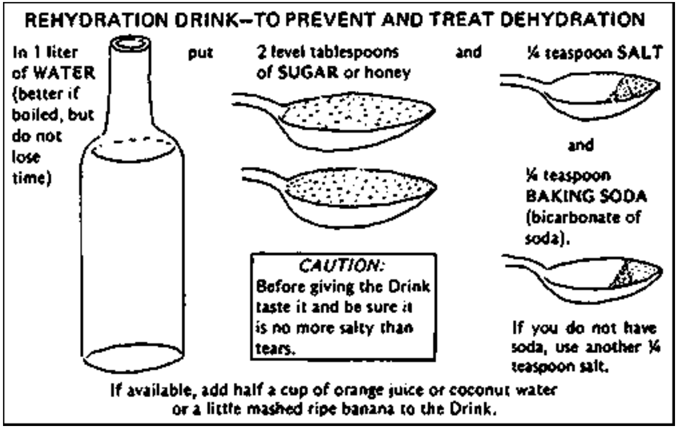
- **Know the signs of meningitis and get (or begin) treatment quickly.**



Figure

- **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. 151 to 161.**

Preventing dehydration helps prevent fits and brain damage (cerebral palsy).



Figure

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 to 43, and 62 to 66.

Throughout the book, important information about cerebral palsy has been marked with a

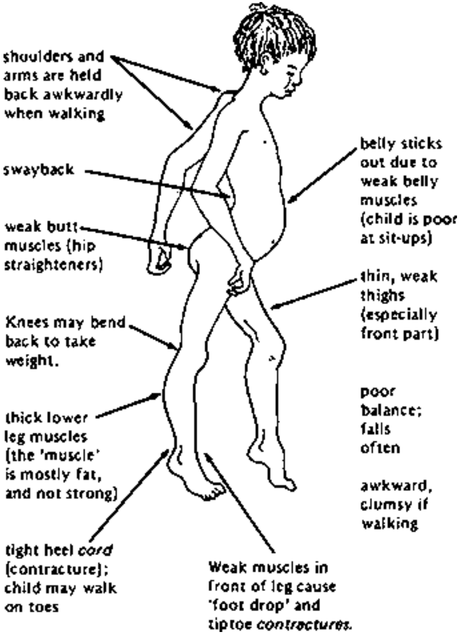
CP in the margin. Many references to cerebral palsy are also included in the INDEX.

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’.

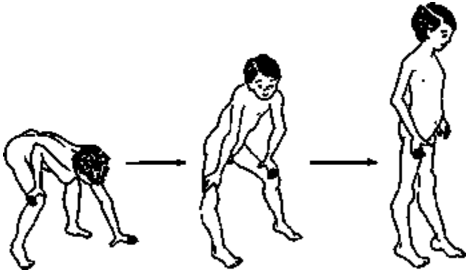
HOW TO RECOGNIZE IF MUSCLE WEAKNESS IS CAUSED BY MUSCULAR DYSTROPHY

- 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.



Figure

Early common sign of muscular dystrophy



Figure

- **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

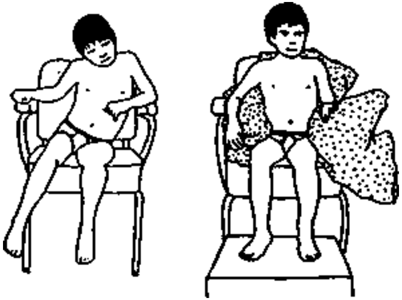
How common is it? It is not very common. *Rehabilitation* centers may see one child with muscular dystrophy for every 30 or 40 with cerebral palsy or polio.

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, exercises and braces to prevent contractures may help the child to keep walking longer. If the child sits in a bad position, pillows or supports to help him sit straighter can help prevent deformities.



Figure

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.

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.

Figure

The goal of the family is to help the child be as active and happy as possible, and to adjust to his increasing limitations.

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 42), 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.

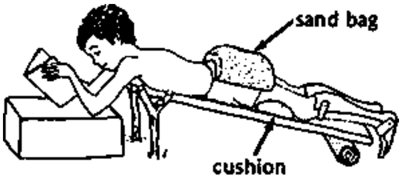
Figure

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 58.)

Figure

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.

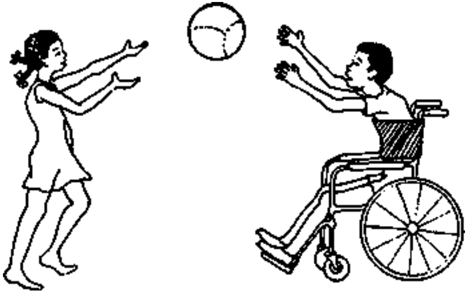
Figure



Figure

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 Chapters 64 to 66.) At first, the child may be able to roll it himself. But as his weakness progresses, he may need to be pushed.



Figure

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 exercises for the lungs.

Figure

Other problems

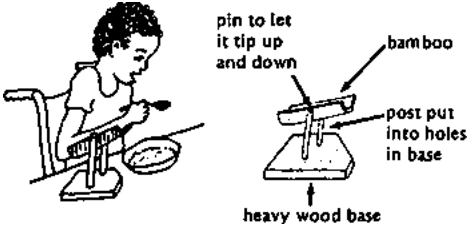
- **Getting fat is a common problem in children with dystrophy. The child needs to eat a healthy balanced diet. But take care not to let him eat too much - especially sweet things. Extra body weight will make walking, breathing, and other activities more difficult for his weakening body, and will make 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.**

- **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.**

- **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.



Figure

CAUTION: If elbow contractures develop, it is probably better to leave them, as a bent elbow is more useful than a stiff, straight one.

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.

Figure

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 there 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 problems.

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.

CURVED FEET: NORMAL in the first weeks or months of life

Figure

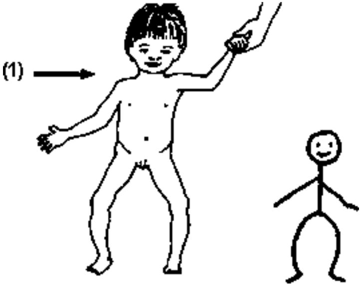
‘FLAT’ FEET: NORMAL until age 2

Figure

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.

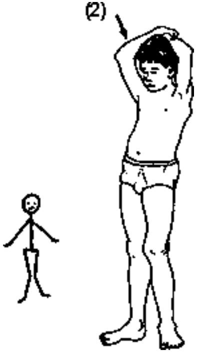
3. A baby’s legs often bend outward (‘bow legs’), like this. (1) This bending starts to disappear at the age of 18 months. Then the legs slowly straighten until they actually bend inward a little, like this. (2)

BOW LEGS: NORMAL until about 18 months



Figure

KNOCK-KNEES: NORMAL between 2 and 12 years



Figure

4. This ‘knock-kneed’ position generally develops around age 2. By age 5 or 6 the knees begin to straighten.

CP

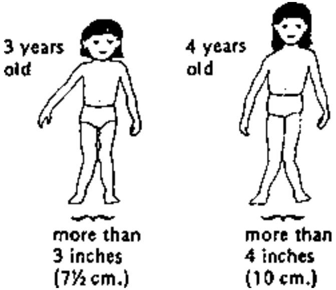
Note: Children with brain damage sometimes develop a ‘knock-knee’ way of standing or walking. If the child with knock-knees also moves or walks in a stiff or jerky way, or shows other problems, check for signs of brain damage. (See Chapter 9 on cerebral palsy.)

IMPORTANT: **In any child who develops bow legs or knock-knees, check for signs of rickets and other problems. See Chapter 13.**

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.



Sign of a problem

If the knock-knees are severe, braces may help straighten the knees and keep the condition from getting worse. 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.

CLUB FEET

club foot before correction

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.

Sometimes a newborn baby's feet turn inward, just because they were in that position in

the mother’s womb.

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.

Figure

Figure

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

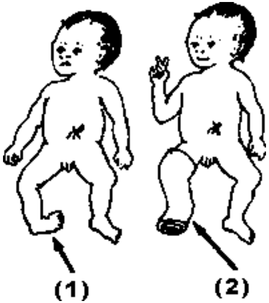
If you cannot put the foot in a normal position, it will need to be straightened with strapping or casts (see Chapter 60).

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.

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.

Correcting club feet (For details, see Chapter 60.)



Figure

A club foot (1) should be held in a cast (2), 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.

Figure

A brace is used (day and night if necessary) to keep the foot from bending in again,

Figure

until finally, normal use and exercise keeps the foot straight,

Figure

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 60.

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, and 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.

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.**

Figure

- **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)**
- **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 a clubbed hand or stiffness in the knees or elbows), club feet may be especially difficult to correct. Usually surgery is needed.**

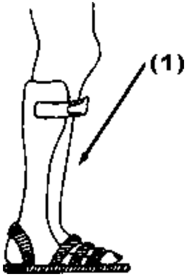
- **The older the child, the harder it is to correct a club foot. Past the age of 2 years, it is often not possible without surgery.**

- **Children without feeling in their feet (spina bifida) require special precautions and slower correction to avoid pressure sores. 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

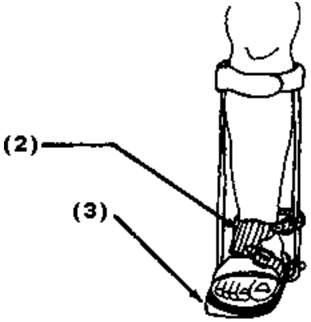
For some feet, a plastic ankle brace (1) may work well.



Figure

For more difficult feet, a metal brace may be needed, with an ankle strap that pulls the ankle inward (2).

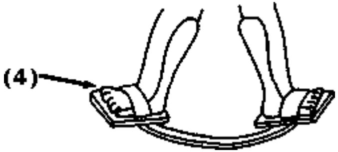
A slight build-up on the outer edge of the sandal or shoe may also help (3).



Figure

For instructions on making braces, see Chapter 58.

For babies under one year, or small children at night, feet can be held in a good position using a bar that joins the feet (4).

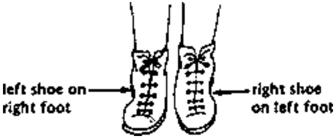


Figure

For the child whose feet bend mostly at the middle or front

Figure

wearing shoes in reverse may help keep the feet corrected.



Figure

FLAT FEET

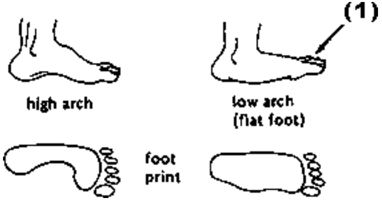
Most children whose only problem is flat feet really have no problem at all - except that poorly informed doctors or greedy special-shoe salesmen make their parents think so!

Most babies have naturally *fat* feet, which can look *flat.*

Normal foot of a child under 2 years old

Do not confuse a FAT foot with a FLAT foot!

In older children and adults there is a lot of natural variation in people's arches.



Figure

Even a foot as flat as this (1), if it causes the child no pain, need not be considered a problem. Often flat feet run in families. If parents or relatives have similar feet but no pain, or if the child can move his feet strongly in all directions, do not worry about it.

Do not worry about flat feet if there is no pain, obvious weakness, or loss of movement.

Children who are late beginning to walk often have weak arches with flat feet, until their feet get stronger.

CP

Even children with very flat feet seldom develop a problem or have more than average pain or discomfort when they do a lot of standing or walking. Usually flat feet are a problem only when paralysis or brain damage is the cause - as in some children with polio, cerebral palsy, or spina bifida. Also, children with Down syndrome sometimes have flat feet that may lead to pain or discomfort.

Correcting flat feet

Figure

The best treatment to help the child with flat feet and no other problem may be to go barefoot. Walking barefoot on sand or rough ground helps the feet get stronger and form a natural arch. Walking on tiptoe, skipping rope, and picking things up with the toes may also help.

BEWARE of going barefoot where hookworm is common.

Figure

CP

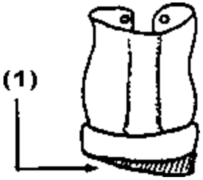
***CAUTION:* Special exercises, training in 'foot posture', shoe adaptations, heel wedges and shoe inserts (heel cups and insoles) are often prescribed to correct flat feet. However, studies show that usually none of these help. Use of insoles to support the arches may even cause weaker arches. Usually insoles should be tried only when pain is a problem, or in some severe flat feet caused by polio, cerebral palsy, or Down syndrome.**

WARNING: THIS METHOD USUALLY DOES NOT WORK

Some specialists try to straighten a foot that is tilted like this

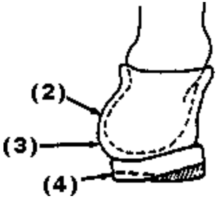
Figure

by putting a wedge under the heel of the shoe like this (1).



Figure

But instead of straightening the foot, this often causes further deformity, because the heel slides to the side (2), and the shoe stretches here (3) and wears out here (4).



Figure

INSOLES AND OTHER FOOT SUPPORTS

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.

An insole is a firm pad that is put inside a shoe or sandal to support the arch.

Figure

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.

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 cannot 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 use a 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 (1).

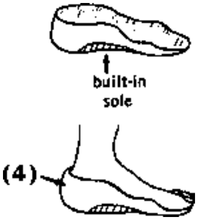
CORRECT

It should ***not*** be in the middle of the arch, like this. This can deform the foot more without correcting the problem (2).

***WARNING**:* Many commercial insoles, and even orthopedic shoes, have the arches in this incorrect position (3). 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.

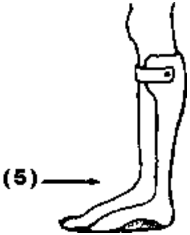
WRONG

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 (4),



Figure

or a brace that supports the foot and ankle, like this (5).



Figure

For instructions on making plastic braces, see Chapter 58.

There is probably only one shoe or sandal alteration that does any good. A small metal plate on the inner edge of the heel (6) stops uneven wear - and may help prevent foot pain.

Figure

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:

- **Poor nutrition during early pregnancy. This is thought to be one cause of cleft lip and palate.**

The mother of this girl with cleft lip and palate did not get enough to eat while she was pregnant.

- **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.

- **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.**

A doctor gave this boy's mother a medicine for 'morning sickness'.

- **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.**

Figure

- **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.

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 children.

Put the breast deep into the mouth so that the milk comes out on the back of the baby's tongue.

Figure

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.

Figure

To prevent choking, feed the baby while he is sitting up with his head tilted forward a little.

Figure

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.

Figure

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. The child who cannot get surgery may need to learn sign language, using her hands to help people understand her.

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.

Figure

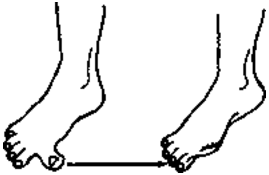
When a child is born with a small extra finger or toe that has no bone in it, you can tie a string tightly around it, like this. In a few days the finger will dry out and fall off.

Figure

Larger extra fingers or toes, if they get in the way, can be removed by a surgeon.

Figure

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.



Figure

To get the best results, the surgery should be done by a specially trained *orthopedic* or plastic surgeon.

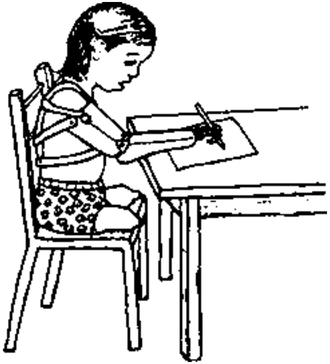
INCOMPLETE OR MISSING ARMS OR LEGS

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.

Figure

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.



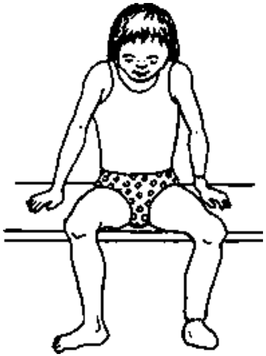
Figure

The child who is born with incomplete arms and legs can be helped a lot by artificial arms with hooks for grasping.

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 67, “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.



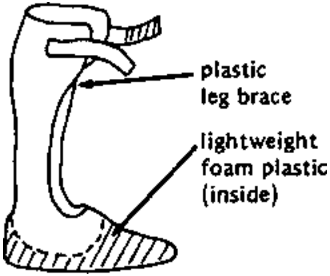
Figure

Her foot looked like this.

Figure

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 58). The plastic brace was heat molded over this.



Figure

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.

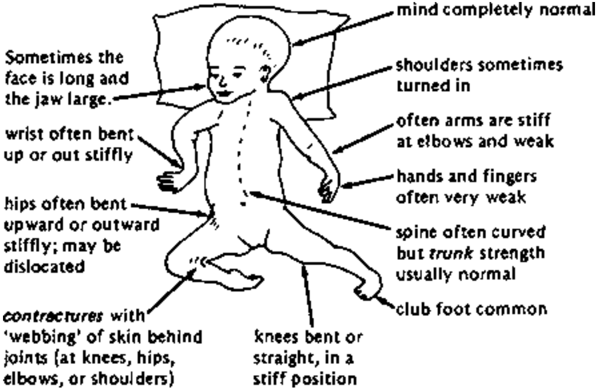
Figure

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



Figure

The **cause** of arthrogryposis is not known. It may be a ***virus infection*** of 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 and hip and knee contractures should begin gradually, and without forcing, soon after birth, with casting, positioning, and/or range-of-motion exercises.

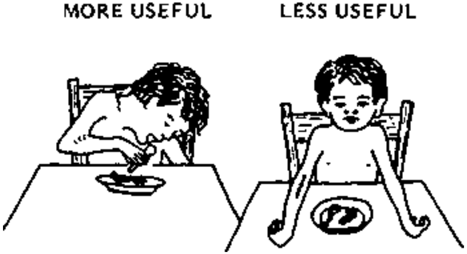
TYPICAL STANDING POSITION OF A CHILD WITH ARTHROGRYPOSIS

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.

Figure

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.

***WARNING:* A STIFF ELBOW IS OFTEN MORE USEFUL LEFT BENT**



Figure

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 Mazatln, 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.

Figure

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.

Figure

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:

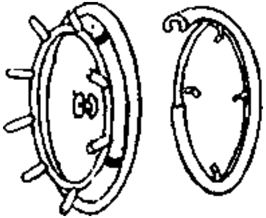
Eating aids are described in Chapter 36.

Figure

Writing aids are shown in Chapter 1, Chapter 27 and Chapter 53.

Figure

Wheelchair aids are shown in Chapter 64.



Figure

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 *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.**

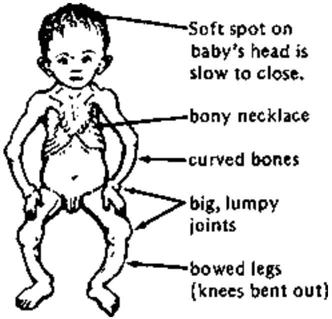
- **Consider not having more children after age 35 or 40, or if you have had one child with Down syndrome, since the chance of having another is increased.**

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



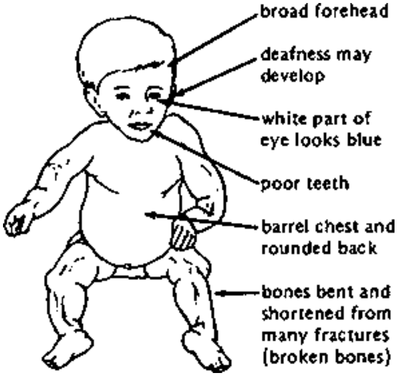
SIGNS OF RICKETS

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 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.

BRITTLE BONE DISEASE



SIGNS OF 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.

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.

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.**

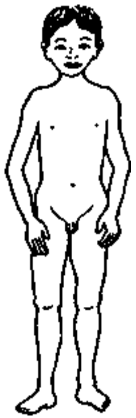
- **Normal short size. When one or both parents are shorter than average, they may have children who are also short. Shortness 'runs in the family' and this is normal. Make sure the child is healthy and eats well.**

- **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. They may also need more stimulation, play, love, and attention in order to grow and develop more quickly (see Chapter 35).**

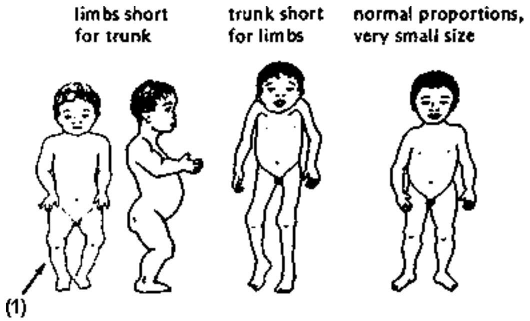
- **Long-term illness or medication. Severe long illness often slows down a child's growth. Also, certain medicines such as cortisone or steroids for arthritis, if given for a long time, can slow down growth and weaken bones.**

- **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.



NORMAL



THREE TYPES OF DWARFISM

In the most common type of dwarfism (1), 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 their age. CHILD-to-child activities can help other children become more understanding (see Chapter 47).

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).

Figure

The baby lies with one arm and hand twisted backward and does not move the arm as much as the other.

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.

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 butt first (breech) because the shoulder is easily stretched and the nerves injured.

Severe Erb’s palsy in 14 year old boy. This is as high as he can lift his arm.

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.

Figure

Then raise the arm straight over the child’s head.

Figure

When the child is old enough, have him do exercises himself, for range of motion and to increase strength.

Ask him to lift his arm as high as he can, turning the palm up as far as he can,

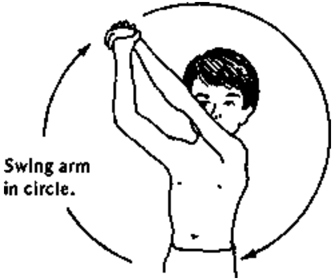
Figure

and then lift it with the other hand as high as he can, with the palm up.

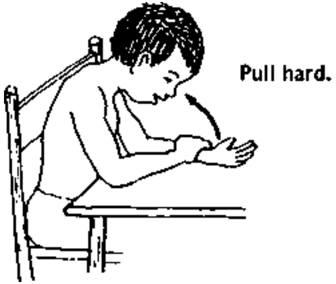
Figure

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.**

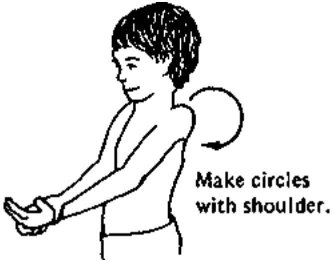
Other helpful exercises



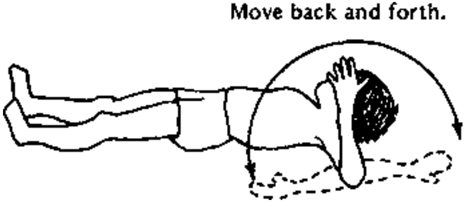
Figure



Figure



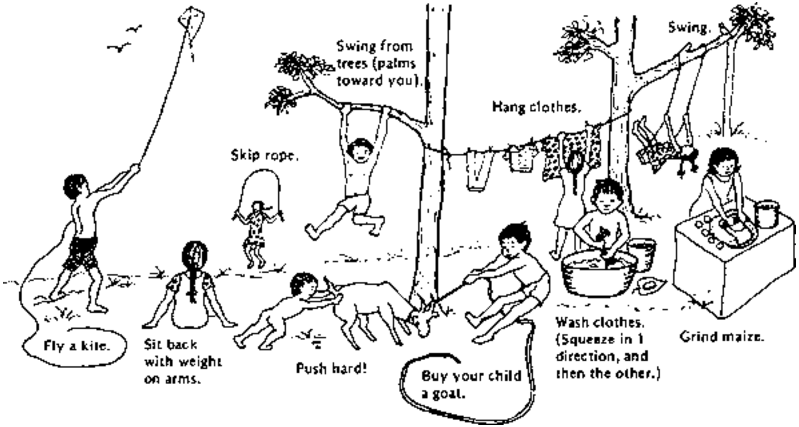
Figure



Figure

Figure

Look for ways to include these exercises in work and play.



Figure

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

Figure

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.*

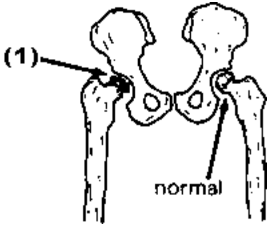
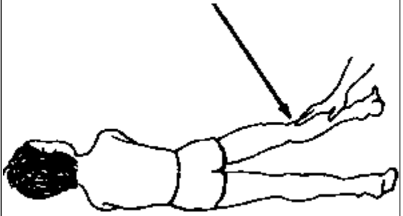
***CAUTION:* Try not to confuse similar illnesses.** Two of the most common causes of joint pain in children are **rheumatic fever** and **juvenile arthritis.** Even some doctors and health workers get them mixed up and diagnose juvenile arthritis as rheumatic fever. The two illnesses do have similarities. 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	Tr
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	• pe days thro (or hea • as dose prec • res

		 **Figure**		• 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	• ra (RO • Ap cold join
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.  **Figure** (In 1/3 of children it begins in only **one** joint - later it may affect others.)	**Figure** Often some fever when pain is worst. (Rarely, it begins with high fever.)  **Figure**	• 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 • one or both eyes may become red and sore (iritis) and become damaged  **Figure**	• as dose prec avoi upse • Ap cold join • RC • ex mot stre mus • lot also acti • lot

				• usually lasts for years with periods when it gets better and then worse	und supp
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: (1) Cap of head of thigh bone breaks into pieces and gradually re-forms in 2 to 3 years  **Figure** 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  **Figure**	• Fo it m do r alth spec reco cast surg • Fo to p the may

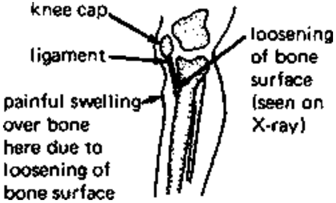
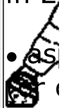
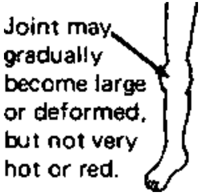
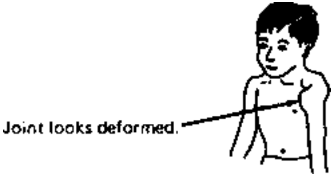
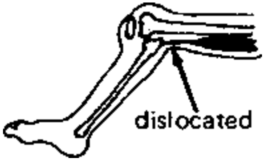
below-knee pain (Osgood-Slater's problem)	Boys 11-18 years old	usually **one** knee only  **Figure**	no fever	• especially in very active, strong boys • may begin with pain after jumping, running, or forceful exercise	• Av exer acti goes in 2  • as or pain • Th last in ti awa the rem
'hot' infection 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	• Ide infe nee • Tre appr anti • Ap avoi

				 **Figure** • joint destruction may be severe-leading in time to a fused or 'frozen' joint, or dislocation	acti earl
'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)  **Figure**  **Figure**	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.	• an med for a (See ***The*** ***Doc*** • da exer • as soak • 'ex with keep stre

		often much pain (sometimes no pain until the bone or joint damage is severe)			
sprains and **torn ligaments**	older child or adult	**one** joint only  **Figure** 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.	• Ap first spra days • Av keep posi • as • Pr tem with adh or (i case ankl
injury to joint surface (for example: torn meniscus,	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	• Pr with ban

bursitis)				weak at certain times but not at others • Swelling or 'liquid' under skin may form behind knee or on the edge of joint.  **Figure**	• re acti • ge exe • as • If cont help
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.  **Figure**	• Ha expe pers the its s sam afte dislo Olde and ones surg • Pr

					for a with ban (esp shou kne • Ge exer day.
dislocated joint due to muscle weakness or muscle imbalance	occurs in older child with polio, other paralysis, or arthritis	usually **one** joint  **Figure** 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.  **Figure** • Careless stretching exercises may cause or	• Tr disl back • Av that agai • Fo disl kne stre exer - bu avoi disl

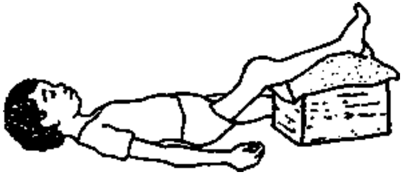
				increase dislocation.	

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.



Figure

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).

Figure

Dip the hand or painful joints into the hot wax.

Figure

Take it out. The wax will quickly harden.

When it cools, dip it in again.

Figure

HOT SOAKS

1. Boil water. Let it cool until you can hold your hand in it comfortably.

Figure

2. Wet a thick cloth or towel in hot water and squeeze out the extra.

Figure

3. Wrap the cloth around the joint.

Figure

4. Cover the cloth with a piece of thin plastic.

Figure

5. Wrap with a dry towel to hold in the heat.

Figure

6. Keep the joint raised.

7. When the cloth starts to cool, put it back in the hot water and repeat.

3. PAINKILLERS

Usually aspirin works best, because it reduces both pain and inflammation.

Figure

***Note:* For severe pain, splints to prevent motion help reduce pain and prevent contractures.**

4. RANGE-OF-MOTION (ROM) EXERCISES

Figure

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 42.)

5. EXERCISES WITHOUT MOTION

Figure

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.

6. CONTINUE DAILY ACTIVITIES

Figure

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).

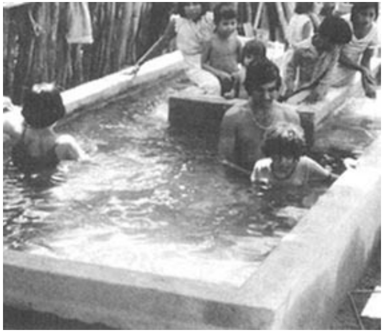
Designs for therapy baths

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.

Figure

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.



Figure

TUBS OR TANKS OF SUN-HEATED WATER (solar heating)

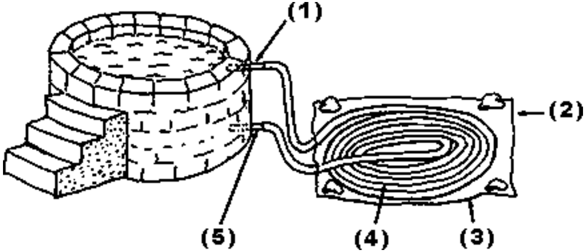
Bathing in warm water is especially helpful. The penetrating heat of the water helps to improve blood flow, calm pain, and relax the muscles.

Figure

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.)

Figure

TUB WITH A SELF-CIRCULATING SUN HEATER



Figure

(1) Because warm water weighs less than cool water, the hot sun-heated water will rise and run into the tank here.

(2) In order for the water to keep flowing, the hose heating unit must be below the level of the tub.

(3) sheet of clear plastic over the hose

(4) black hose

(5) The cooler water will run out here.

INFORMATION ON ASPIRIN FOR SWOLLEN JOINTS IN PERSONS WITH ARTHRITIS OR

INFORMATION ON ASPIRIN FOR SWOLLEN JOINTS IN PERSONS WITH ARTHRITIS OR RHEUMATIC FEVER

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 **every day.**

- 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 ‘heartburn’), 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 Milk of Magnesia (magnesium**

sulfate), Maalox, or **Gelusil.**

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 like 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

500 mg. tablets:

Adults: 2 to 3 tablets, 4-6 times a day
Children, 8-12 years: 1 tablet, 4-6 times a day
Children, 3-7 years: half a tablet, 4-6 times a day
Children, 1-2 years: one-quarter tablet, 4-6 times a day

Figure

If there are no swollen joints, use another medicine just for pain. This is very important if aspirin causes too many side effects. For other medicines for pain, see the Green Pages in ***Where There Is No Doctor.***

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. (1¼ 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

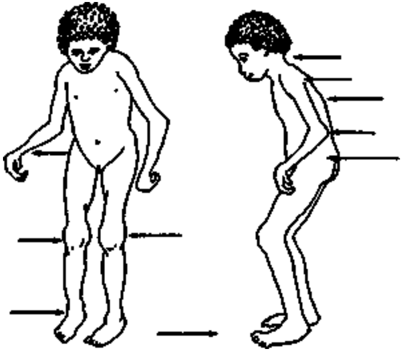
- **The arthritis (joint pain) often begins between the ages of 5 and 10, but may begin in very young children or teenagers.**

- **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

- **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).**

- **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.***

- **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.**

Figure

- **Children with severe arthritis in the neck and jaw may have a small, short chin.**

Figure

- **The fingers may become very thin and deformed, or thick, with slender tips.**

Figure

- **Wrists and ankles may become stiff and bent.**

Figure

- **Contractures may develop in the fingers or toes, and with time the bones may fuse (stick together).**

More information about JUVENILE ARTHRITIS

There are 3 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 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.

Figure

Medicines that generally should NOT be used:

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, steroids should be used only when the child’s life or eyesight is in danger. Steroid eye-drops at the first signs of iritis can prevent blindness.

‘moon face’ and hump of fat on the back of the neck, caused by steroids

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.

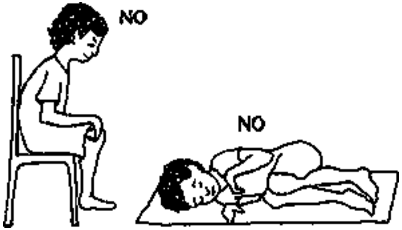
Indomethacin (Indocin), phenylbutazone, and related medicines are so *toxic* that they should not be given to children.

☠	***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.

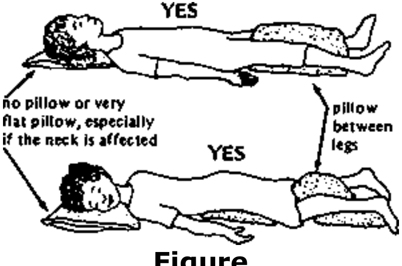


Figure

Although it may 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.

In these positions, contractures are less likely to develop.



Figure

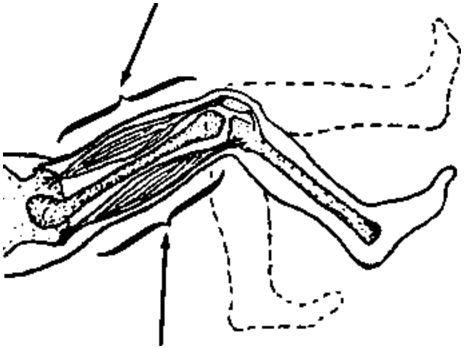
Rest and sleep with the arms and legs as straight as possible. Use pillows only in a way that gently helps the joints straighten more. Let the legs slowly straighten under their own weight.

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.

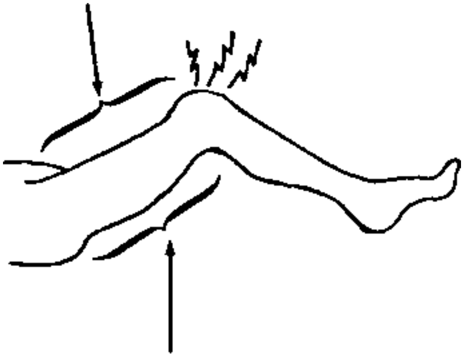
HOW PAIN CAUSES CONTRACTURES

When these muscles are tightened, they straighten the knee,



Figure

Because it hurts to straighten the knee, the child with arthritis does not use these muscles much. So they become very weak.



Figure

Since the muscles on top are weaker than those below, the uneven muscle strength keeps bending the leg more and more, even during sleep.

Figure

and these muscles bend it.

But these muscles stay tightened to keep the knee bent and guard against pain. So they stay stronger.

NOTE: This kind of uneven muscle strength is called ***muscle imbalance****.*

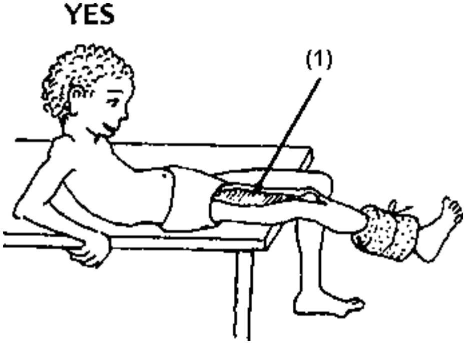
Because contractures from arthritis result mainly from unequal muscle strength, it is important that the child do all exercises and activities in ways that will strengthen the weak muscles that straighten the joints, not the muscles that bend them. For example:

Do exercises that work this muscle.

This is the muscle that straightens the knee and prevents contracture (1).

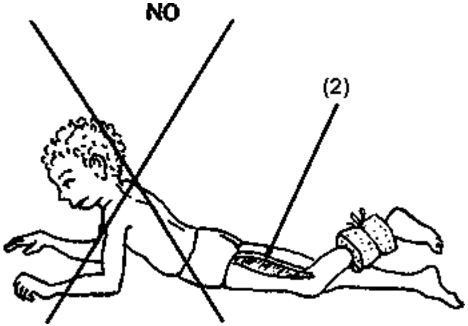
But do **not** do exercises that work this muscle.

This is the muscle that bends the knee and causes a contracture (2).



Figure

STRENGTHEN MUSCLES THAT STRAIGHTEN THE JOINT.



Figure

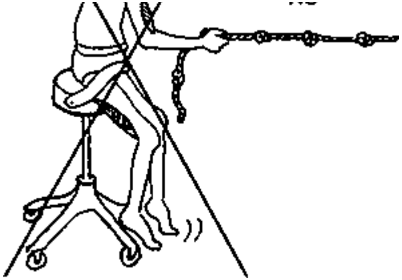
DO NOT STRENGTHEN MUSCLES THAT BEND THE JOINT.

Follow this same logic with all exercises and activities. And look for ways to make the exercises useful and fun.

For example, Alicia has arthritis and can no longer walk by herself or straighten her arms and legs completely. As a way of moving herself about and getting some exercise, she can sit on a chair with *casters,* as shown here. But she should be careful to move in a way that helps prevent contractures.

Pulling herself forward with her arms and legs exercises mostly the muscles that **bend** the joints.

Pushing herself backward, with her arms and legs, does more to strengthen the muscles that **straighten** the joints.



Figure

This can make contractures worse.

Figure

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.

Even if the child herself tries to straighten her elbow, the pain will cause the stronger, bending muscles to tighten.

Figure

The muscles that straighten the elbow will not be used - and will get weaker.

Figure

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.

Figure

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 (1), to take more weight on her arms.

Figure

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 the llama in the eye.

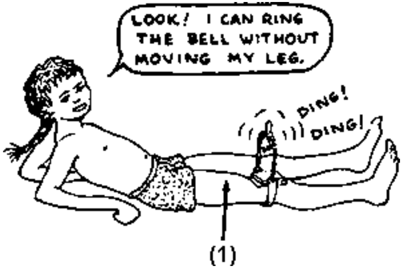
> ***Note:* We have shown these exercises in a girl who already has contractures. But it is best to start them before contractures begin.**

You can figure out similar exercises without motion for all the weak muscles that need

strengthening to help prevent or correct contractures.

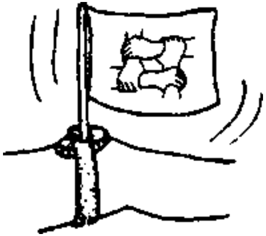
For example, to strengthen the knee-straightening muscles, the child can lie on her back with her leg as straight as possible. Have her tighten the muscles on top of her thigh (*without* tightening those underneath) and count to 25. Then relax and repeat 10 times. She should do this 3 or 4 times a day Again, look for ways to make it more fun.

Tightening this muscle (1) pulls the kneecap and rings the bell.



Figure

You can strap a small bell or flag to the leg, so that it will ring or move when the knee bone moves.



Figure

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

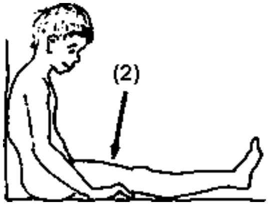
First do the exercise without motion lying down.

Tighten here (1) without moving and count to 25. Relax and repeat 10 times. Do it 3 or 4 times a day.

Figure

After a few days, do it sitting up.

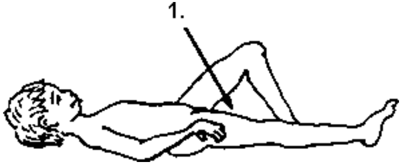
Tighten here (2) without moving.



Figure

Second exercise: straight leg raise

1. With the leg straight, tighten the muscles on top of the thigh (as in the first exercise).



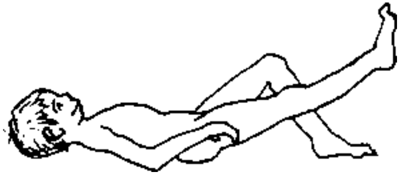
Figure

When you lift the leg, be sure that the knee points up or slightly (1) out to the side.

Figure

2. Then lift the leg without bending the knee, and slowly count to 5 or 10.

3. Lower the leg slowly.



Figure

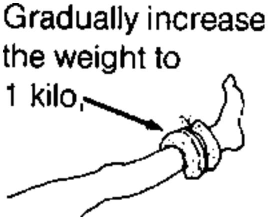
4. Rest.

Do not let knee bend at all (2). (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.)

Figure

When the child can do this exercise lying down without bending his knee, begin putting weights on his leg:

Figure



Figure

Figure

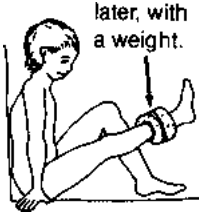
For the weight, you can use a small bag full of sand.

Figure

After a few days, have him do the same exercise sitting up:*

*** *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.**

Figure



Figure

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.

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.

Figure

1. Tighten the muscle on top of the thigh.

Figure

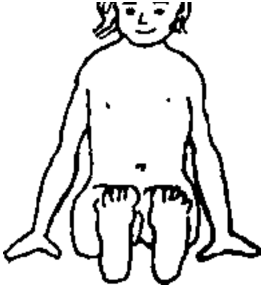
2. Lift the leg, keeping it straight.

Figure

3. Move the leg to the side and turn it outward.

Figure

4. Move the leg back in and turn it inward.



Figure

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

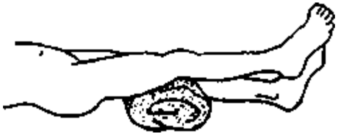
1. Lie down with a rolled towel or blanket under the knee.

Figure

2. Turn the leg out to the side.

Figure

3. Lift the foot and slowly count to 5 or 10.



Figure

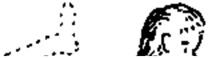
4. Lower it slowly.

5. Rest.

6. Repeat the exercise 10 to 30 times.

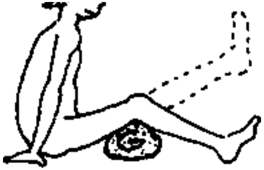
Make sure that only the foot is raised, not the thigh, and that the knee is lifted as straight as possible.

As the child gains strength, continue with the same series of steps as for the second exercise.



Figure

1. Lying down, lift the foot with a weight on it. Build weight up slowly to 5 kilos.



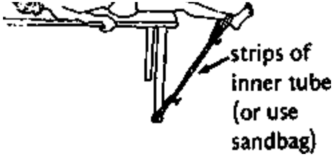
Figure

2. Sitting up, lift the foot without a weight.

Figure

3. Sitting up, lift the foot with a weight. (Build up to 5 kilos.)

Do these 2 exercises only if there is no danger of hip contractures.



Figure

If arthritis or contractures have begun in her hip, it is best to do the exercise lying down with the hip as straight as possible (nothing under the knee).

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 an 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.**

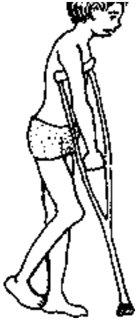
NO

YES

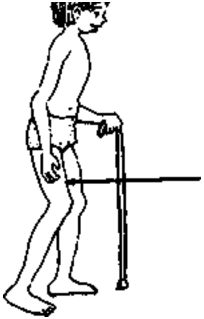
A cane helps strengthen weak muscles and prevent contractures.

If he uses a cane, he must put some

If he uses a cane, he must put some weight on the leg. This strengthens the muscles that straighten the leg.



Figure



Figure

***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.

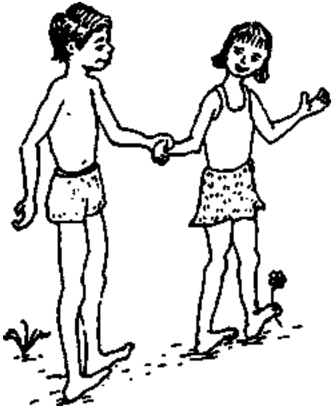
These activities strengthen weak thighs.

Walking uphill exercises the thighs more than walking on flat ground.

Figure

Figure

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.)



Figure

SWIMMING. Swimming is one of the best exercises for a person with arthritis.

Figure

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.

Figure

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.

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).

***Note:* Range-of-motion exercises for different joints are described in Chapter 42. Here we discuss ways to make them easier for children with arthritis.**

Heat helps relax muscles and calm pain. 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.

Figure

Find ways for the child to play in the water. This will help him forget his pain and make straightening the joints easier.

Figure

In moments when she has her leg or arm most straight, ask her to hold that position a moment without bending.

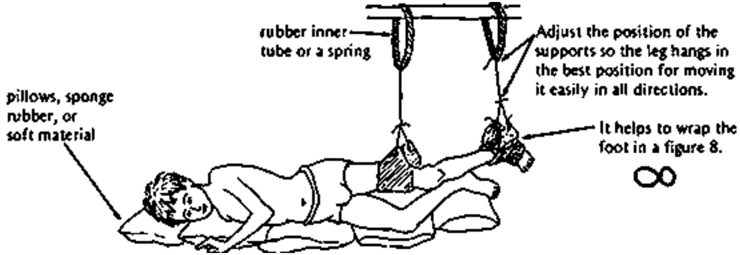
This way, little by little, she will find she can straighten her joints more and more.

Figure

‘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, the leg or arm can be hung in a simple device - loosely, as if floating in water.

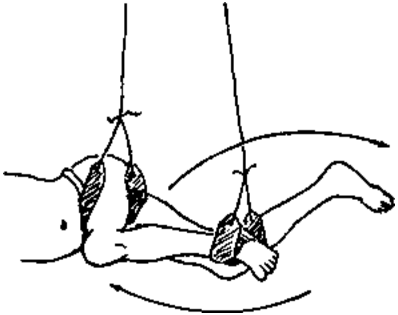
‘FLOATING’ AN ARTHRITIC LEG



Figure

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).

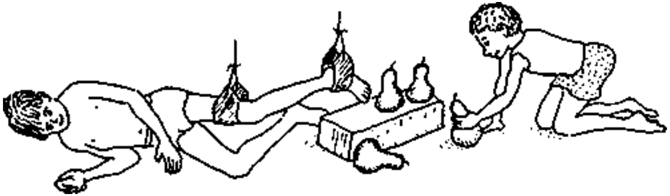


Figure

Look for ways to turn the exercise into a game.

For example, the child might knock gourds or blocks down while another child tries

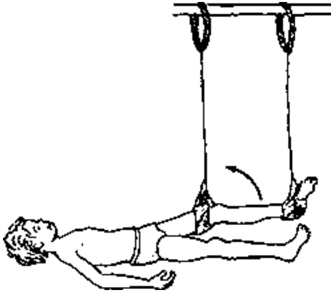
quickly to set them up again, and see who wins.



Figure

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.

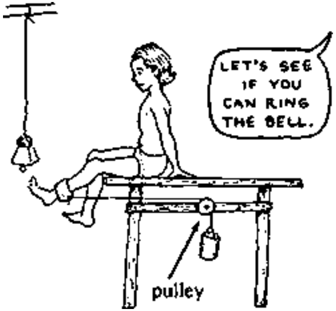
Also have the child do exercises lying on his back and swinging his leg outward (to one side). This helps prevent knock-knee contractures.



Figure

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

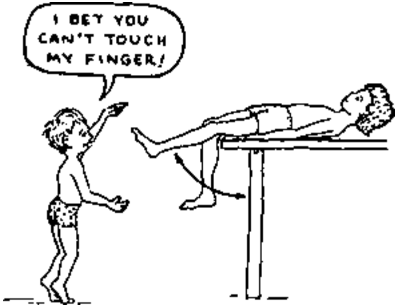
bent.



Figure

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 the leg becomes stronger, add more weight.

The 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.

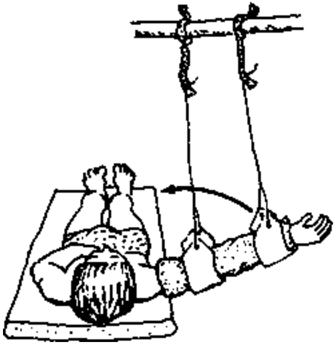


Figure

Movement of the arms. This is done much like the legs:

LYING FACE UP

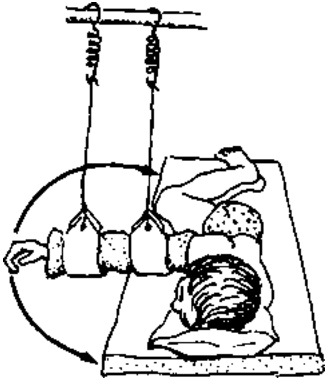
Swing the arm away from the body.



Figure

LYING ON THE SIDE

Swing the arm forward and back.



Figure

AND SITTING

Swing the shoulder and elbow through their full range of motion.

Figure

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.

Figure

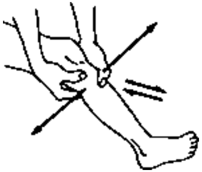
Look for ways to do these movements as part of daily activities.

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 42). For severe contractures, stretching aids or casts may be needed (see Chapter 59). 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

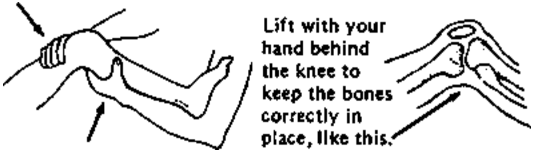
1. First examine the joint for signs of dislocation. Try moving the bones forward and backward and from side to side.



Figure

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.

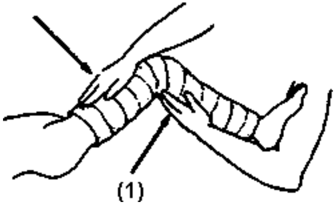


LIKE THIS

CAUTION: **Do not pull like this, or you may dislocate the joint.**

NOT LIKE THIS

3. With the joint as straight as you can get it without too much pain, carefully cast the leg.



Figure

Until the cast dries, apply steady pressure here (1) 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.

Figure

You can cut a hole above the kneecap (2) 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

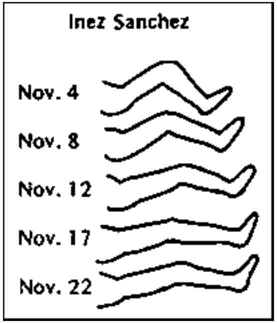
and straightening the leg little by little. Then gently stretch the leg a little more, and put on another cast.

Figure

(*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.



Figure

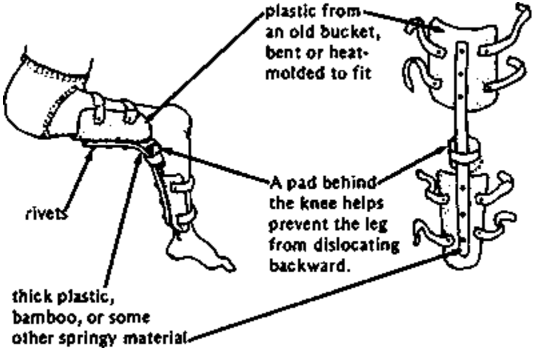
Homemade aids for stretching joints

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.

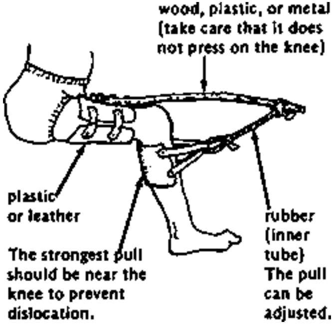
These are a few of the examples of aids invented in a Mexican village for a girl with arthritis.

***CAUTION:* Make sure that the aids pull in a way that does not cause dislocations.**

KNEE



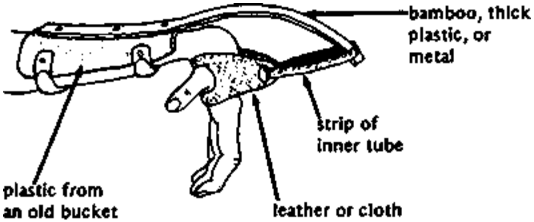
METHOD 1



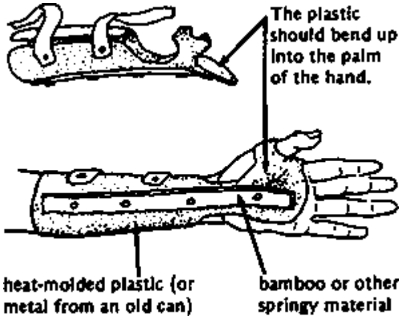
METHOD 2

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.**

WRIST



Over-the-hand support



Under-the-hand support

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 of 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 59.

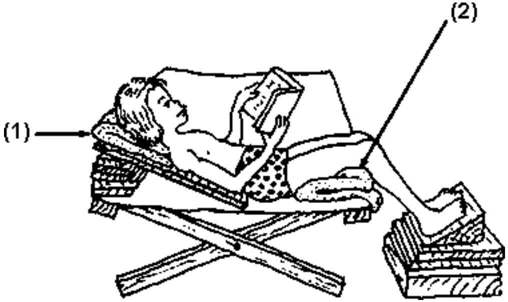
Correcting contractures of arthritic hips

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.

(1) 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.

(2) 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.



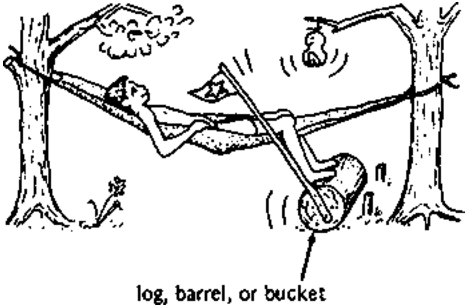
Figure

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.

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.

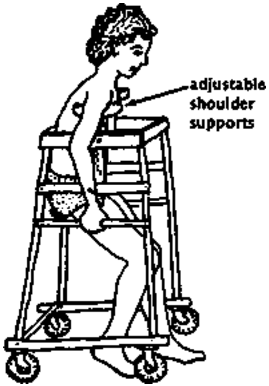


Figure

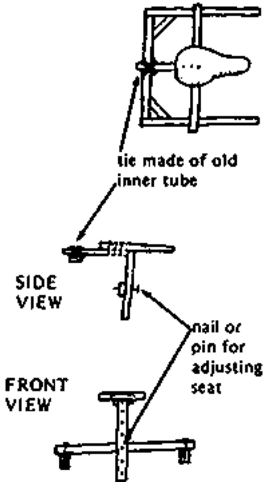
A homemade walker similar to this can help a child with hip contractures begin to walk. It also provides exercise for the straightening muscles of both the arms and legs.

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.



Figure



ADJUSTABLE SEAT

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.

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 59). They changed the casts every 2 days. With each cast change her joints were exercised.

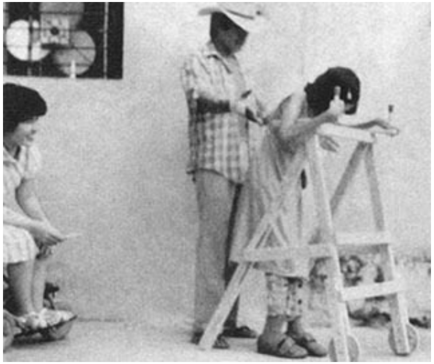
Finally, with the casts, Teresa’s knees and wrists became fairly straight. She now had some hand movement and could play in the playground.

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 wheels. 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.

Figure

Figure

Figure

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. 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. 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
- **High fever** - 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.

Figure

- 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
- **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... whoosh-dub... 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. 325).

- 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.)**

- **Give penicillin by mouth for 10 days; or give a single injection of benzathine penicillin G into the butt *muscles* (one-half in each butt); or inject procaine penicillin daily for 10 days. For children who are allergic to penicillin, use erythromycin. See box for doses. (For *cautions* in the use of penicillin, see *Where There Is No Doctor,* p. 351.)**

- **Give aspirin in high dosage. An information sheet with the dosage and precautions for taking aspirin is in the previouses pages. 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.**

- **Do full range-of-motion exercises of painful joints gently every day (see Chapter 42).**

- **Do 'exercises without motion' to maintain strength.**

- **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**
Penicillin V or G (by mouth)	up to 3 years	125 mg.	4 times a day for 10 days.
	over 3 (includes adults)	250 mg.	
OR			
Benzathine penicillin (by injection)	up to 3 years	600,000 units	single injection (Give one-half in each butt.)
	over 3 (includes adults)	1,200,000 units	
OR			
Procaine penicillin (by injection)	up to 3 years	600,000 units	Inject one-half into each butt muscle once a day for 10 days.
	over 3 (includes adults)	1,200,000 units	
For persons allergic to penicillin give:			
Erythromycin (by mouth)	up to 3 years	125 mg.	4 times a day for 10 days.
	over 3 (includes adults)	250 mg.	
***NOTE**:* Whenever possible, it is safer to give children medicine by mouth than by injection.			

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 a preventive dose of penicillin regularly for at least one attack-free year or until they are 17 years old (after which the risk of strep throat is lower). Long-term prevention is especially important in persons who already have serious rheumatic heart damage.

PREVENTIVE DOSAGES:

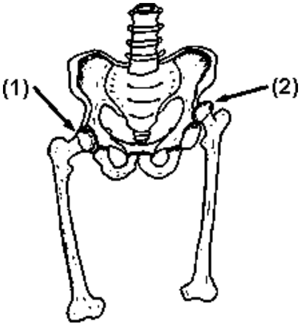
- or 1 injection of 1.2 million units of benzathine penicillin G, once a month,
- or 1 tablet of 500 mg. of sulfadiazine 2 times a day,
- or 1 tablet of 250 mg. of potassium penicillin V, 2 times a day with an empty stomach.
- For children allergic to penicillin, give 1 tablet of 250 mg. of erythromycin, 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. 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.



Figure

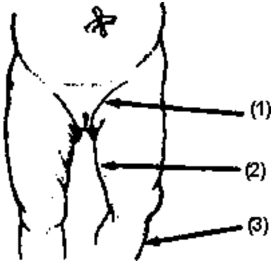
(1) NORMAL HIP: The round head of the thigh bone is *inside* the hip socket.

(2) DISLOCATED HIP: The round 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 (1)**
- **there are fewer skin folds (2)**
- **the leg may seem shorter, or turn out at a strange angle (3)**



Figure

2. Hold both legs with the knees bent, like this,

Figure

If one leg stops early or makes a jump or click when you open it wide, the hip is dislocated.

Figure

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.

Figure

Treatment

Keep the baby with his knees high and wide apart. To do this,

- **use many thicknesses of *diapers (nappies)* like this,**

Figure

- **or pin his legs like this (when the baby sleeps),**

Figure

- **or carry the baby like this.**

Figure

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

CP

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**

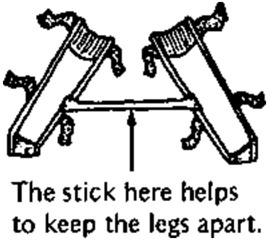
Many (but not all) dislocated hips can be corrected in the ways we described. Keeping the

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.

CAST

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 pee, so it does not run inside the cast.)



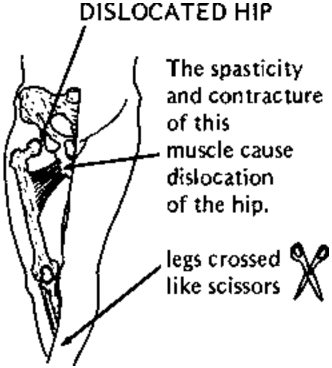
BRACE

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.

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.

CP

Dislocated hips can also occur after the child is born, either from an accident or as a complication of some other 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*).



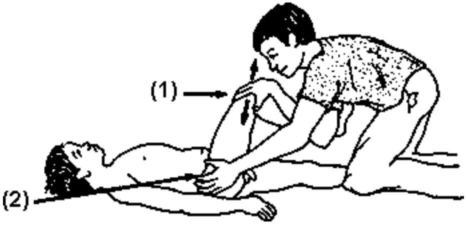
Figure

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 than push it down, like this (1).

At the same time, feel his hip with your other hand, like this (2).



Figure

If the thigh bone moves in and out like a telescope, the hip is probably dislocated.

Figure

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.

HIP PROBLEMS DUE TO DESTRUCTION OR SLIPPING OF THE CAP OF THE THIGH BONE

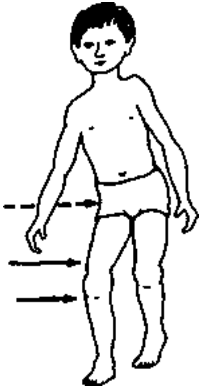
There are 2 different hip problems that occur most often in very active children, usually boys.

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).**

SIGNS:

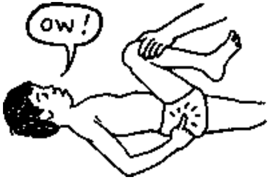
- Child begins to **limp:** body dips toward affected side.



Figure

- 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.



Figure

- Motion for bending, or opening of hip may become somewhat limited, or painful if he tries to bend it more.

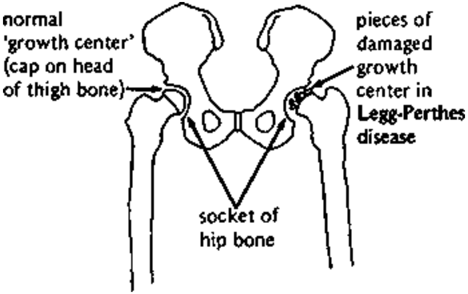
- In time the thigh becomes thinner and weakness develops in the muscles that lift the leg sideways.

Figure

The cause in both cases is often unknown but may be related to an injury caused from jumping or falling.

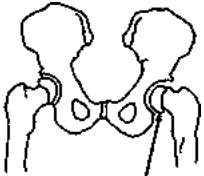
Destruction of the growth center results from a temporary loss of its blood supply, which results in death of the bone.

DIAGNOSIS: If a child has signs of one of these problems, try to get an X-ray to find out the cause.



Figure

Figure



Figure

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

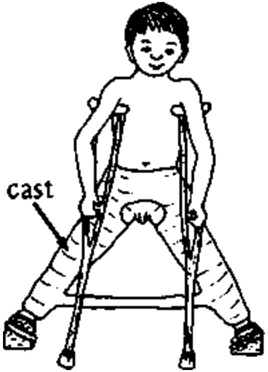
without pain. However, the new growth center is usually flatter than before and does not fit into the hip socket as well. As a result, after several more years, the hip joint begins to wear out and a *progressive,* destructive, painful arthritis may begin.

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.

Figure

A newer method was to cast or brace the legs wide apart.



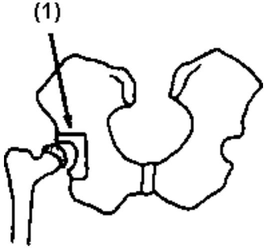
Figure

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 (1) containing the hip socket,



Figure

and turned it (2) so the head of the thigh bone fit deeper into the socket. (The result was similar to widely separating the legs.)

Figure

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 that 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.

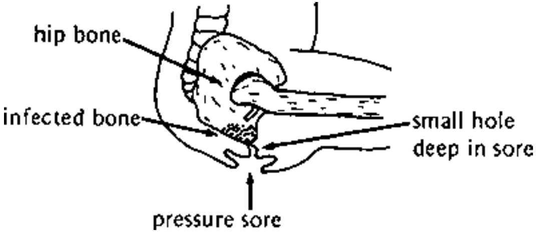
Bone infections are a very common complication of injuries, burns, and pressure sores in persons who have no feeling in their hands and feet. This includes persons with spina bifida, spinal cord injury, and leprosy. Because the person does not feel pain, often she does not rest, clean, or protect the 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.

Figure

***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.**



Figure

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.**

Figure

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).**
- **If you cannot get the pus cultured, you might try treating the infection with tetracycline (by mouth), or 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.**
- **Sometimes amputation is necessary.**
- **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 58 on pressure sores, leprosy, and braces.

When there has been a lot of bone destruction, sometimes a brace can help make walking easier.

Figure

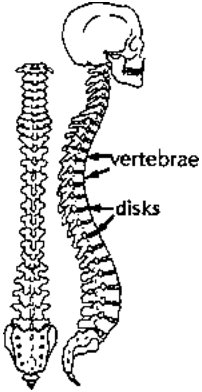
Large hole down to the bone in the foot of a woman with a bone infection (osteomyelitis). She has had this problem since childhood 30 years before.

Figure

***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.**

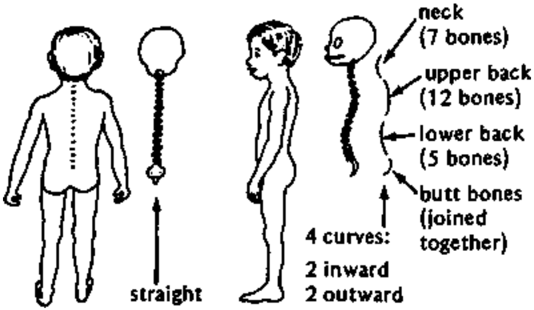
Chapter 20: Spinal Curve and Other Back Deformities

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.



Figure

NORMAL SHAPE OF THE BACKBONE



Figure

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)

Figure

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)

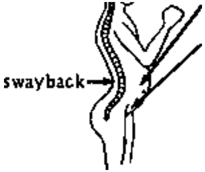
Figure

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.



Figure

Sharp bend or bump in spine

(tuberculosis of the backbone)

Results from destruction of one or more vertebrae by tuberculosis ***infection***

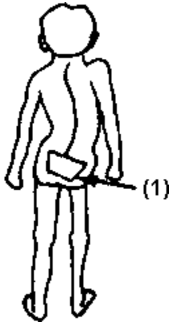
Figure

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

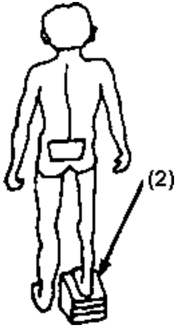
With a non-fixed or '*functional'* curve there is no deformity of the vertebrae. This usually happens when the body tries to stand straight even though the hips tilt or there is other unevenness not in the spine.

For example, a child with a shorter leg from polio will stand with his hips tilted (1). For him to stand straight, the spine has to curve.

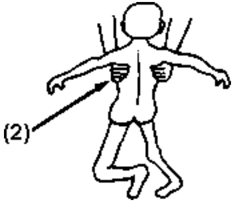


Figure

A non-fixed curve can usually be straightened by putting blocks under the foot (2), or by holding the child up under the arms.



Figure



Figure

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.

Figure

***Note:* In some cases, with time a non-fixed curve may gradually become fixed.**

CAUSES OF SPINAL CURVE (SCOLIOSIS)

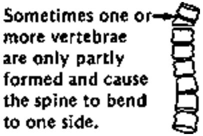
Most scoliosis (about 80%) occurs in otherwise healthy children for no known reason. Sometimes it occurs in several members of the same family, so there may be a *hereditary* (familial) factor. Although about 1 of every 10 persons has some scoliosis (if looked for), only about 1 in 400 has enough of a curve to be a problem. Curves of unknown cause are often first seen - and progress quickly - in children from 10-16 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.

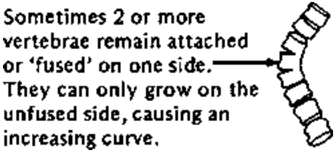
Some children are born with fixed scoliosis, or develop it in early childhood, because of defects in the spine itself.

These problems can only be identified by X-rays.



Sometimes one or more vertebrae are only partly formed and cause the spine to bend to one side.

Figure



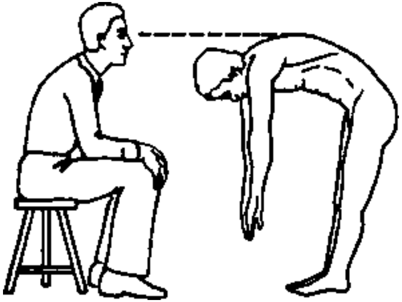
Sometimes 2 or more vertebrae remain attached or 'fused' on one side. They can only grow on the unfused side, causing an increasing curve.

Figure

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

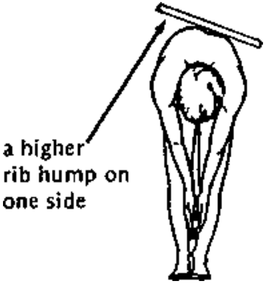
This is discussed in the chapter on physical examination (Chapter 4).



Figure

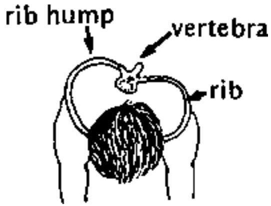
Look along the line of the back with the child bent over.

Figure



Figure

The rib hump is formed because where the spine is curved, the vertebrae also are twisted to one side.

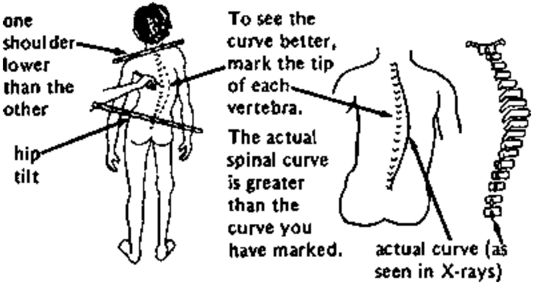


Figure

POSSIBLE SIGNS OF EARLY SCOLIOSIS

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

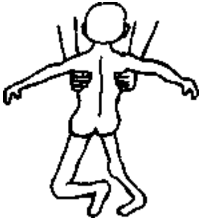
CHECK FOR:



Figure

overhead view of vertebrae

When you examine for scoliosis, also check to see if the curve



can be straightened (non-fixed),

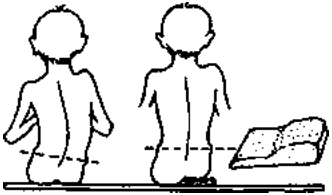
or cannot be straightened (fixed).

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 butt is weaker and smaller, it may cause a **hip tilt.**



Figure

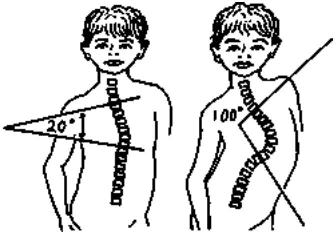
Put a book or board under the weaker butt, and see if this straightens his spine. If so, a cushion raised on one side may help him sit straighter.

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.

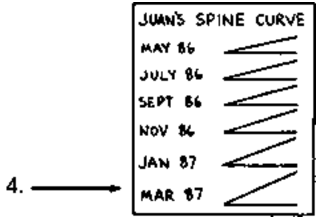
2. Draw lines level with the top of each vertebra.

3. Measure and record the angle of the spinal curve.



Figure

4. Regularly record the curve and notice any changes.



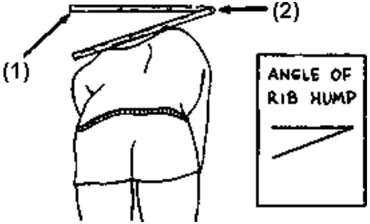
Figure

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.

Have the child stand or sit as straight as possible, while he bends forward.

Be sure the top piece is completely level (1). You can use a carpenter's level or a homemade one (see box).

Measure this angle (2).



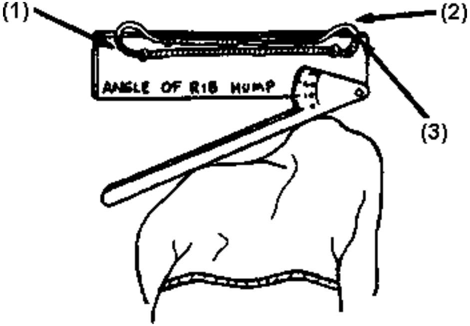
Figure

A home made level for measuring rib hump angle

Fill the tube (1) with colored water so that the water reaches the top edge of the board at both ends when level.

(2) piece of thin plastic tube (old I.V. tube)

When measuring the rib hump, level the top (3) by making sure the water is at the top edge of the board at both ends.



Figure

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

Figure

Level the hips by standing on books or boards.

Figure

Put a lift on shoe or sandal

Figure

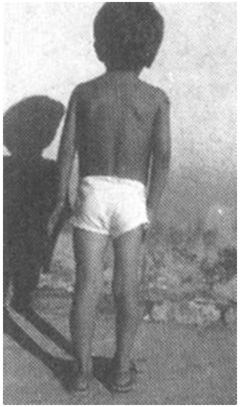
This child was developing a spinal curve due to hip tilt and short leg.

Figure

Village rehabilitation workers put a lift on his sandal.

Figure

This corrected his spinal curve and lop-sided posture.



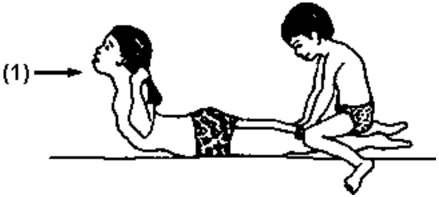
Figure

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.

Figure

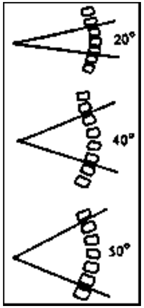
Spinal curves under 20° (fixed or non-fixed) usually need no special care - other than to be watched, and measured every few months to see if they are getting worse.

Some experts say that exercises to strengthen the back muscles, like this (1), help correct and slow down the curving of the spine. Other experts say it does no good. (We do not know.)



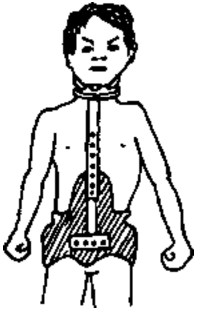
Figure

Spinal curves over 20°, if they are fixed and getting worse, may get worse less quickly with a brace.



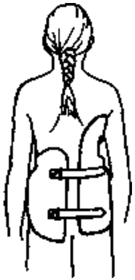
Figure

A brace like this (the Milwaukee brace) 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.



Figure

A plastic 'Boston brace' like this is more comfortable, can be completely hidden under the clothes, and probably does as much good.



Figure

SURGERY

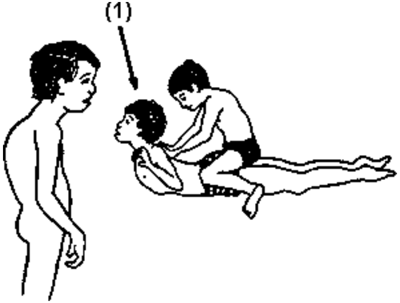
For spinal curves over 50° which are quickly getting worse, surgery may be needed. Surgery 'fuses' (joins together) the most affected vertebrae. Usually it only partly straightens the spine. Except for very severe curves, surgery should be avoided in children under 12 years old because the fused part 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 (1).

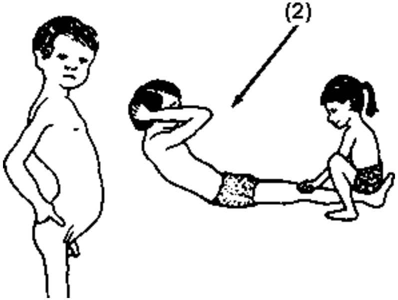


Figure

These exercises are explained in the Exercise Sheet #5.

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 (2),



Figure

or by exercises to correct hip contractures (if the child has them). See Exercise Sheet #3.

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 *nerve* damage and *paralysis.*

If a child begins to develop a sharp bend in the middle section of the backbone, with shortening and thickening of the chest, it is probably tuberculosis of the spine. You can almost be sure it is, if someone in the family has TB of the lungs.

As the *spine* collapses forward, the child may have to hold himself up using his arms.

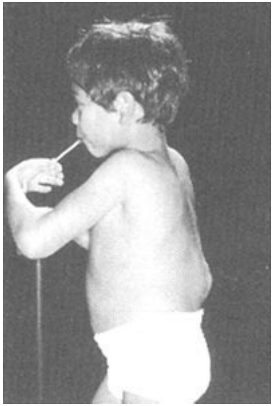
Figure

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.



Figure

Figure

- 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 open lower on the body and drain pus.

- As the condition gets worse, back pain may begin.

- Signs of **spinal cord** injury may develop: pain, numbness, weakness or paralysis in feet and legs, and loss of urine and bowel control. (See “Spinal Cord Injury”)

- 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 half of children with TB of the spine also have TB of the lungs.

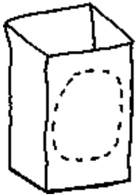
Treatment

- **Use 2 to 3 TB medicines for at least a year, as for TB of the lungs. (See *Where There Is No Doctor,* p. 180.)**

- **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.**

Or make a very simple back brace from a metal tin or drum:

1. Cut an oval piece from a heavy tin.



Figure

2. Hammer the tin to fit the child's back. Without forcing, try to put the back in the straightest position possible.

Figure

3. Pad the tin and wrap it with a soft cloth.

Figure

4. With an elastic bandage, bind the plate firmly to the child's back.

Figure

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.

- **In severe or advanced cases, surgery may be needed to help straighten and stabilize the bones of the spine.**

CAUTION: Because of the risk of paralysis, an orthopedic surgeon should be consulted if possible.

Hopes for the future

With early, complete treatment the damaged bones will usually heal and the child may live normally, although often somewhat hunched over.

If nerve damage and paralysis have begun, sometimes surgery (or even bracing during treatment) can bring some improvement.

When nerve damage is severe, *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 poverty. Vaccination against TB may also help.

Chapter 22: Spina Bifida

WHAT IS IT?

Spina bifida (also called meningocele or myelomeningocele) is a defect that comes from a problem in the very early development of the unborn child. It happens when some of the back bones (vertebrae) do not close over the center tube of *nerves (spinal cord).* As a result, a soft unprotected area is left, which may bulge through the skin as a dark bag. This ‘bag of nerves’ is covered by a very thin layer (membrane) which may leak liquid from the spinal cord and brain. Nobody knows what causes it. But 1 of every 250 to 500 babies is born with spina bifida.

Figure

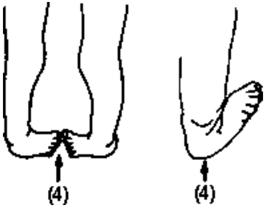
Problems that occur with spina bifida

(1) High risk. Without early surgery to cover the bag of nerves, it almost always gets *infected* and the child dies of meningitis .

(2) Muscle weakness and loss of feeling. The legs or feet may be paralyzed and have little or no feeling.

(3) Hips. One or both hips may be *dislocated.*

(4) The feet may turn down and in (club feet), or up and out.

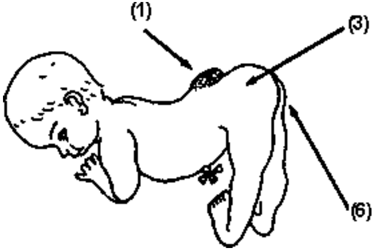


Figure

(5) 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.**

(6) 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.



Figure

(7) 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.

(8) very big head

(9) big veins

(10) The eyes may turn downward because of pressure in the head. This ‘setting sun sign’ means danger of blindness and severe brain damage.

Figure

(11) 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), or develop cerebral palsy (see Chapter 9).

PROBLEMS THAT MAY OCCUR WHEN THE CHILD IS OLDER:

(1) Curve of the spine (See Chapter 20.)

(2) Urinary infections and kidney damage

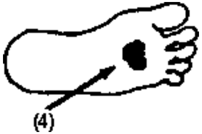
Figure

(3) Pressure sores may form over the bones, because the child cannot feel. (See Chapter 24.)

Figure

(4) 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.



Figure

What is the future for a child with spina bifida?

This will depend first on how serious the defect is, next on medical treatment and general care, and finally on special training and on family and community support.

Figure

The higher up the back the defect is or the more severely the spinal cord is affected, the worse the paralysis and other problems are likely to be. If the head is already very swollen, the child's chances are poor. The costs will usually be great, even for a rich family. Surgery to drain the liquid from the head is sometimes followed by infection. The operation may need to be repeated several times. In spite of the best medical attention, at least 1 of every 4 or 5 children born with severe spina bifida dies in the first months or

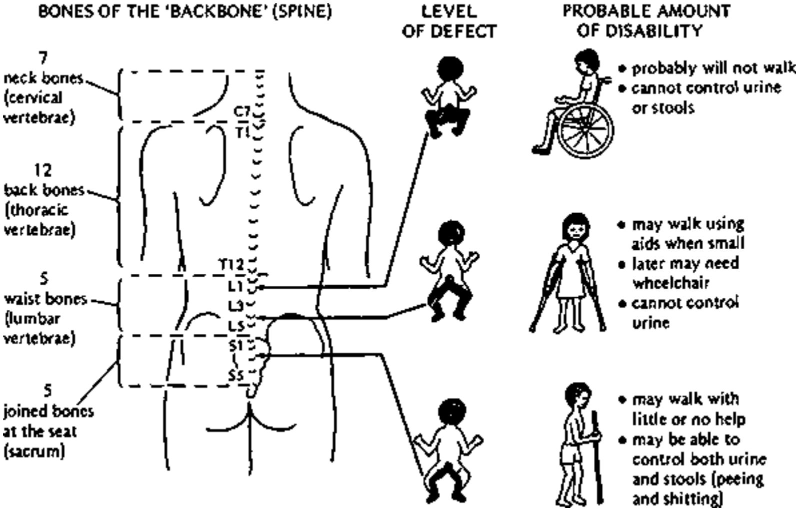
years of life.

However, the child with a defect that is low down on the back usually has less paralysis, and has a good chance of living a full and happy life. With good family and community support, many children with spina bifida go to school, learn to do many kinds of work, get married, and have children.

Often these children are late in learning basic skills for self-care (getting dressed, eating, going to the bathroom). 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.

What are the chances that my child with spina bifida will walk?

This depends on many factors. However, the higher up the defect is on the spine, the more paralysis the child will probably have. The drawings below show how likely it is for the child to walk, based on the level of the defect. The shaded areas show the parts of the body affected by paralysis and loss of feeling.



Figure

CARING FOR THE CHILD WITH SPINA BIFIDA

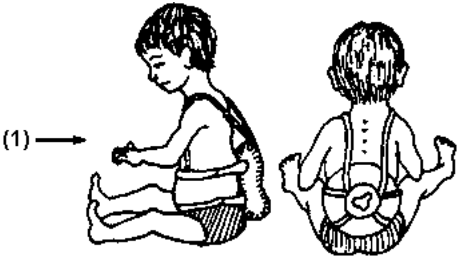
BEFORE SURGERY

AFTER SURGERY

Care of the defect. When there is a 'bag of nerves' on the spine of a newborn 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. Without this operation there is a high risk of injury and brain infection (meningitis); the child will probably not live very long.

For children who cannot get an operation, try to protect the bag of nerves so that its thin covering is not injured or broken. (If it breaks, meningitis can occur.)

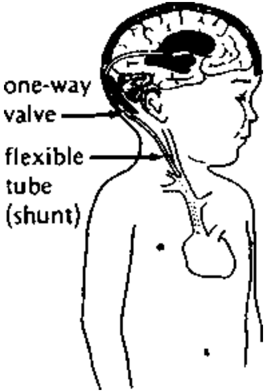
One way to protect the bag is to make a ring or 'donut' of soft cloth or foam rubber (1), and to tie it so that it surrounds the bag. Do not let the ring or clothing touch the bag.



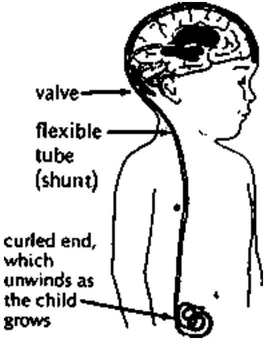
Figure

Hydrocephalus. It is important to measure the distance around the head of the child at birth, and every week or so afterward. If head size increases faster than normal (see chart), 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. A tube is run from a liquid-filled hollow in the brain into the entrance to the heart or into the belly (abdominal cavity). This way the extra liquid is drained from the brain.



SHUNT-BRAIN TO HEART



SHUNT-BRAIN TO BELLY

Not all children who have early signs of hydrocephalus need this operation. If the head is not very swollen and stops increasing rapidly in size, it may get better by itself.

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. Others 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 very 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 peeing (bladder control) and shitting (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. In children with spina bifida, urinary infections are a frequent cause of death.

Figure

A mother can learn to feel how full the bladder is, and to tap on it gently to see if this makes the baby pee. If not, she can regularly press gently on the bladder to push out the urine.

Figure

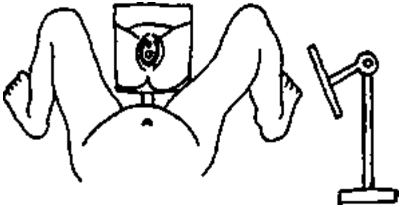
Later, some children can learn to empty their bladders by crying, rolling over, laughing, or sneezing. Others learn to do it by pressing on the stomach, like this, although this can also be risky.

Figure

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.

Figure

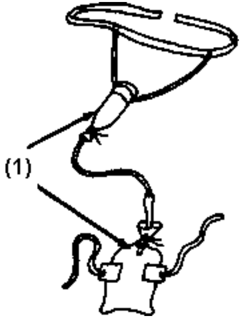
Girls often need to empty the bladder regularly with a catheter, and perhaps use diapers (nappies) to catch any urine that drips out in between.



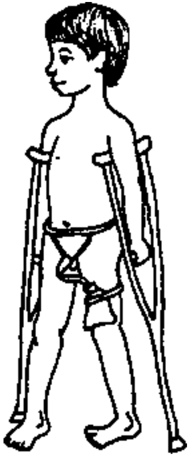
Figure

For girls, a mirror helps in finding the urine hole.

As they grow older, boys are often able to use a ‘condom’ connected to a bag (1) that collects the urine.



Figure



Figure

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.

IMPORTANT INFORMATION on **urinary and bowel problems** and **prevention and treatment of urinary infections** is in Chapter 25. Be sure to study this chapter!

PREVENTION and correction of contractures

Some children with spina bifida tend to develop *contractures* either because of muscle imbalance or, less often, because of *spasticity* (abnormal muscle tightness). Contractures

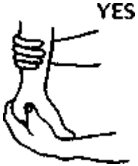
most often develop in the feet, hips, and knees. Range-of-motion and stretching exercises, as discussed in Chapter 42, can help prevent and correct early contractures.

***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:*

If the foot is stiff in this position,

Figure

do exercises to gradually bring the foot up.



Figure

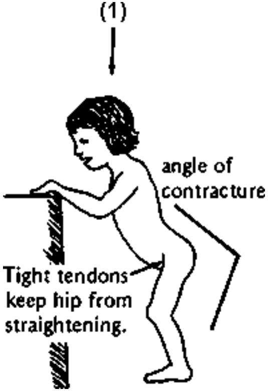
But if the foot is floppy or already bends up more than normal,

Figure

avoid exercises that would stretch it even more.

Figure

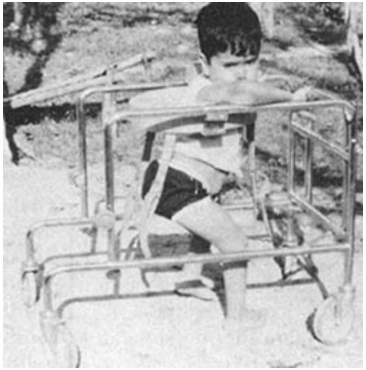
Because children with spina bifida have stronger muscles for bending than for straightening the hips, they tend to develop hip contractures, like this child (1). Stretching exercises and lying on the belly may help.



Figure

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.



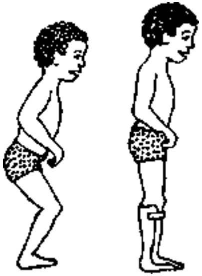
Figure

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.

Figure

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.



Figure

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.

Figure

Do not let the child get fat.

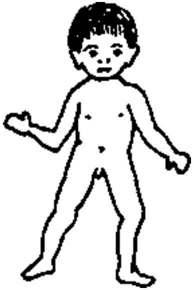
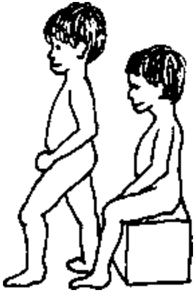
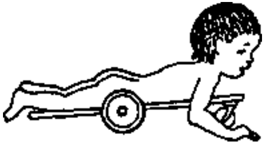
Because the legs and feet of a child with spina bifida are weak, it is important that she does not get too heavy. Even for a child who does not walk, moving will be easier if she is not fat. Encourage her to eat nutritious foods, but to avoid a lot of sweets, fatty foods, and sweetened drinks.

HELPING THE CHILD DEVELOP

Many children with spina bifida are paralyzed from the waist down. In spite of their

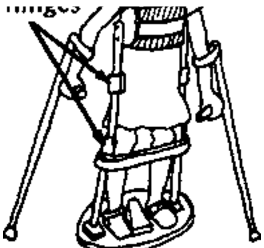
disability, it is important for them to develop their bodies, their minds, and their social abilities as much as possible. Certain 'adaptive aids' can be used to help paralyzed children go through the same stages of development as able-bodied children, at close to the same age. (See the developmental chart)

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				
 **Figure**	 **Figure**	 **Figure**	 **Figure**	 **Figure**
SPINA BIFIDA				
 **Figure**		 **Figure**		

Figure

Figure



Figure

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.

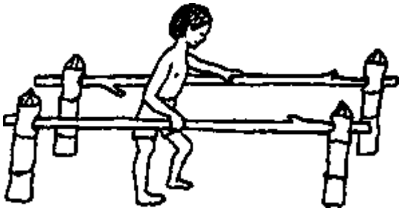
You can make a seat from an old bucket or some other object, so that she can sit and play.

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.

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 58). Other children will need wheelchairs.



Figure

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.

Figure

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. So that the contractures do not come back, the children will need to do exercises and perhaps use simple plastic braces, at least at night.

For curving of the spine, if severe, some children need surgery or a body brace.

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”)

***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 butt or his feet). To prevent this:

- **Have the child sleep and sit on a mattress or cushion that is soft (such as foam rubber), and move or turn over often.**
- **Examine the child’s lower body daily for early signs of irritation or sores. Check especially the hips, knees, and feet.**
- **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.**

Figure

Also, be sure that sandals, shoes, and orthopedic braces fit well and do not cause blisters or irritation.

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.

Figure

IMPORTANT INFORMATION on prevention and treatment of pressure sores is in Chapter 24. **Be**

IMPORTANT INFORMATION on prevention and treatment of pressure sores is in Chapter 24. **Be sure to read** it. Also see Chapter 26 on Leprosy for special footwear and ways to protect the feet.

You will find other important information that relates to a child with spina 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.

This child with spina bifida was born to a village family too poor to afford surgery.

The PROJIMO team made her a special seat with a bowl attached to a hole in the back to protect her ‘sack on the back’.

A child with spina bifida learns to walk with the help of a homemade walker. (PROJIMO)

A one-year-old with spina bifida in a mini wheel-chair made by disabled workers (PROJIMO)

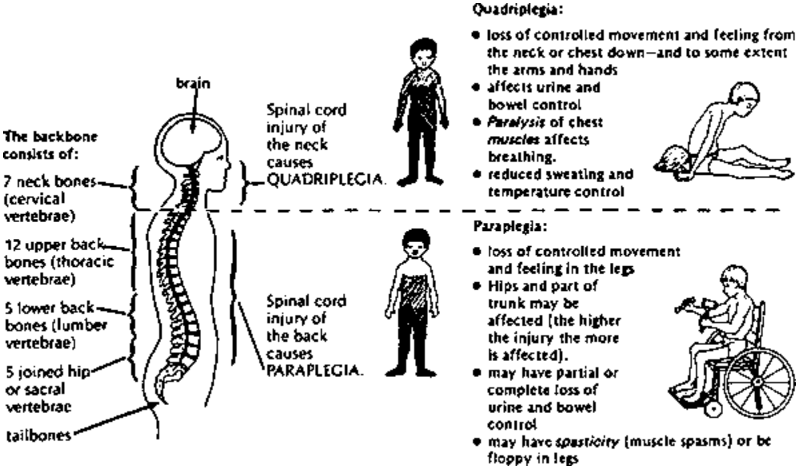
Chapter 23: Spinal Cord Injury

Spinal cord **injury usually results from an accident that breaks or severely damages the central** ***nerve cord*** **in the neck or back: falls from trees or mules, automobile accidents, diving accidents, bullet wounds, and other injuries. Spinal cord injury is more common in adults and older children - and in many cultures it is twice as common in men as in women.**

The ***spinal cord*** **is the line of** ***nerves*** **that comes out of the brain and runs down the backbone. From the cord, nerves go out to the whole body. Feeling and movement are controlled by messages that travel back and forth to the brain through the spinal cord. When the cord is damaged, feeling and movement in the body below the level of the injury are lost or reduced.**

Level of the injury

How much of the body is affected depends on the level of the injury along the backbone. The higher the injury is, the greater the area of the body that is affected.



Figure

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’, 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 cord 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

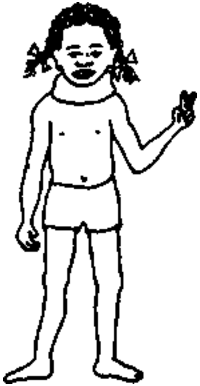
“Will my child always remain paralyzed?”

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. The more time goes by without improvement, the less likely it is that any major improvement in feeling or movement will occur.

Occasionally surgery to release pressure on the spinal cord or nerves, if done in the first hours or days following the injury, will bring back some movement or feeling. But surgery done more than a month after the injury almost never brings back any movement or feeling. Never agree to such surgery unless at least 3 independent and highly respected neurosurgeons recommend it.

It is *very* unusual that a child who is paralyzed by a broken neck is walking with a neck collar in 6 weeks.



Figure

After one year, 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 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.

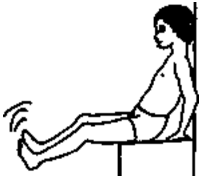
"My child's feet are beginning to move!" - spasticity

Immediately after a spinal cord injury the paralyzed parts are in 'spinal shock', and are loose or 'floppy'. 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.

***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.



Figure

Some children with spinal cord injury develop spasticity; others do not.

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

level between 1st and
2nd lumbar vertebrae

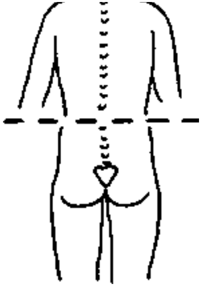


Figure FLOPPY

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.

Figure

In lower back injuries, the spasticity or stiffness of the legs may actually help the child stand for *transfers.*

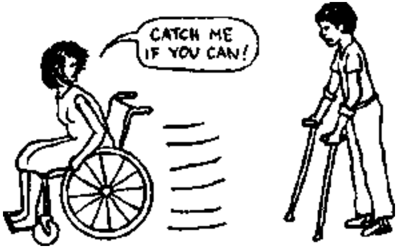
Figure

"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 to go long distances.

Many spinal cord injured persons prefer a wheelchair to walking with braces and crutches.



Figure

However, it is best not to place too much importance on learning to walk. Many children who do learn to walk find it so slow and tiring that they prefer using a wheelchair.

It probably makes sense to give most paraplegic children a chance to try walking. 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.

For independent living, other skills are more important than walking, and the family and child should place greater 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 persons to lead a normal life because they are more dependent on physical assistance. However, in some countries many paraplegics and quadriplegics 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 possibilities 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 CHAPTER!

“What about marriage, sex, and having children?”

Figure

Many spinal cord injured persons marry and have loving, sexual relationships. Women with spinal cord injuries 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. Whether or not they can have children, male and female spinal cord injured persons often enjoy loving sexual relationships.

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.

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.)

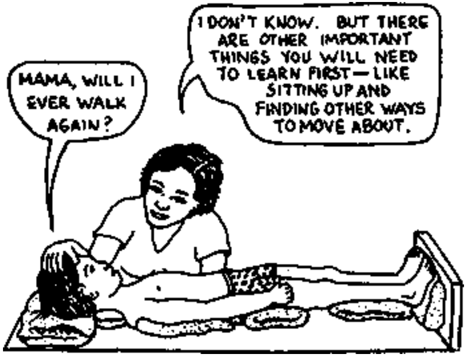
Perhaps the biggest difference from spina bifida is that spinal cord injury begins later. One day the child is physically active and able, the next he is suddenly paralyzed and (at first) unable to do much for himself. He has lost all feeling and control in part of his body; it is like a dead weight.

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 *disability.* Do not tell her, "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.'**



Figure

- **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. Crying helps relieve fear and tension.**

- **Start the child with exercises, activities, and relearning to use her hands and body as soon as possible. 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

Help in ways that let the child do more for herself.

- **As much as possible, avoid ‘tranquilizers’ 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 this book.

Figure

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 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 of strips of clothing, or whatever you can.**

Figure

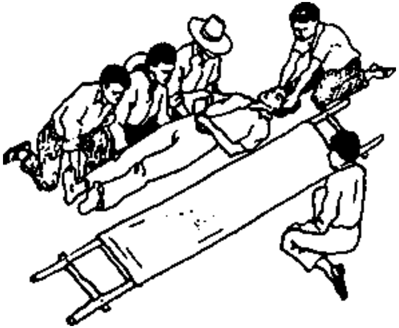
- **Tie him down firmly and stabilize his head.**

- **Carry the person to a medical center or hospital. Try not to bounce or jiggle him.**

HOW TO LIFT A SEVERELY INJURED PERSON ONTO A STRETCHER
from *Where There Is No Doctor*

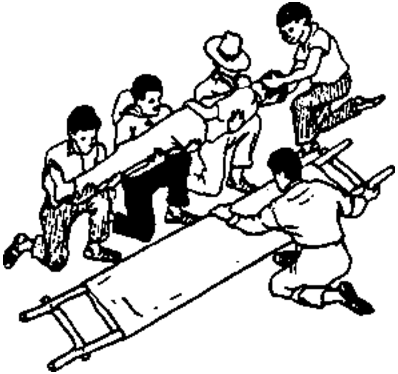
1.

2.



Figure

With great care, lift the injured person without bending him anywhere.

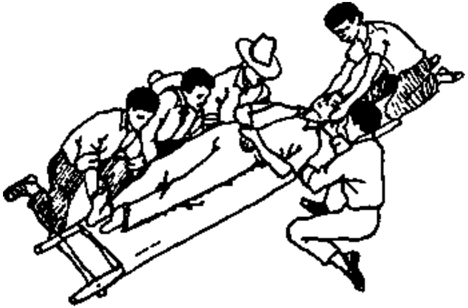


Figure

Make sure that the head and neck do not bend.

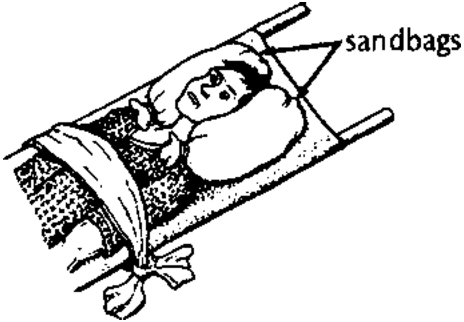
Have another person put the stretcher in place.

3.



Figure

4.



Figure

With the help of everyone, place the injured person carefully on the stretcher.

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

(1) 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.

(2) sudden high blood pressure with pounding headache (dysreflexia) due to irritation in non-feeling parts (quadriplegics only)

(3) periods of depression, anger, and difficulty accepting disability

(4) curving or ‘hunching’ of spine

(5) Child suffers greatly in hot weather because body loses ability to control its temperature.

(6) urinary infections (may involve kidneys and cause death)

(7) pressure sores (bed sores) in-body areas where feeling has been lost (See Chapter 24.)

(8) rash or sores between legs due to loss of urine and bowel control

(9) increased risk of pneumonia in quadriplegics, due to weak breathing muscles

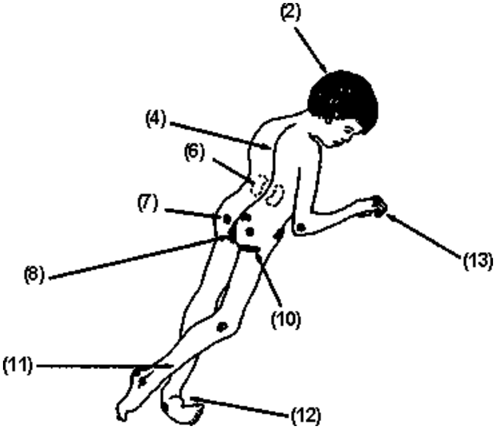
(10) pressure sores caused by long-leg brace

(11) spasticity causes legs to straighten and pull together and feet to ‘tiptoe’ stiffly

(12) contractures - especially of

- **elbows and hands (in quadriplegics)**
- **hips (bend up and pull together)**
- **tiptoe and club foot deformities - especially in small children**

(13) burns or other injury where body cannot feel



Figure

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 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.)

> ***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 change.** Use the same methods and precautions used in lifting a newly injured person onto a stretcher. 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.

Surgery of the spine may or may not be necessary. After surgery, the person must lie very still for at least 6 weeks. The main purpose of surgery is to prevent more damage - not to cure the paralysis. The damage already done to the spinal cord cannot be corrected with surgery or medicine.

Preventing pressure sores (bed sores)

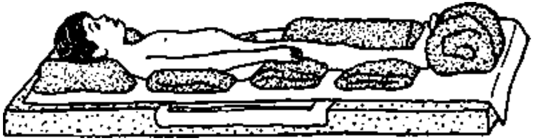
When feeling has been lost, pressure sores can easily form on the skin over bony areas - especially on the hips and butt. The biggest risk of sores is in the first weeks after the injury. This is because the child must stay very still, and has not yet learned to move or turn over his body. Prevention 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 PREVENTION AND TREATMENT OF PRESSURE SORES.**

Summary: early prevention of pressure sores (For details, see Chapter 24.)

- **Lie on a soft mattress or thick, firm, foam rubber pad.**

- **Place pillows and pads to keep pressure off bony areas.**
- **Change position (turn over 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.**
- **Eat good food rich in vitamins, iron, and protein.**
- **Move and 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.**



Figure

Avoiding contractures

In the first weeks following a spinal cord injury, when the child is in a lying position, joint contractures (muscles shortening) can easily develop, especially in the feet and 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.

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.

Figure

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.

Figure

If the person has a lot of mucus in her lungs, it also helps to lie her down, like this (1), and pat her back briskly. This helps loosen the mucus so that it can be coughed out. Be sure she drinks lots of water to help loosen the mucus.

Figure

MOVEMENT AND EXERCISE

Do range-of-motion exercises for about 10 minutes for each arm and leg. In the first weeks, do the exercises 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 42). The exercises will help to improve the flow of blood (which reduces the chance of bed sores), 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.

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 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,

Figure

but not when it is bent back like this.

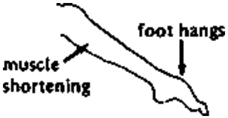
Figure

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,



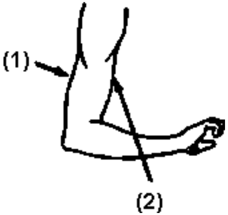
Figure

Prevent this through exercises and by supporting feet.

♦ or, joints that are kept straight or bent by spasticity or by muscle imbalance. For example:

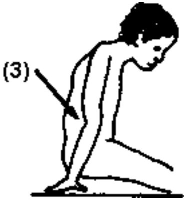
> In quadriplegia the muscles that straighten the elbow (1) are usually paralyzed, while the muscles that bend the elbow (2) stay fairly strong. These muscles keep the elbow bent, and in time they shorten so that the arm can no longer straighten

fully.



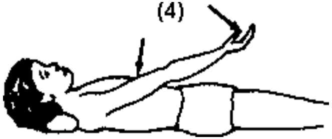
Figure

It is important that the arms can straighten until they bend backward a little (3) - which is the only way he can lift himself with his arms.



Figure

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 (4).



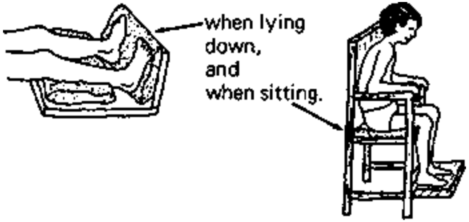
Figure

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:

Teach the child to make sure his feet are in a good position.

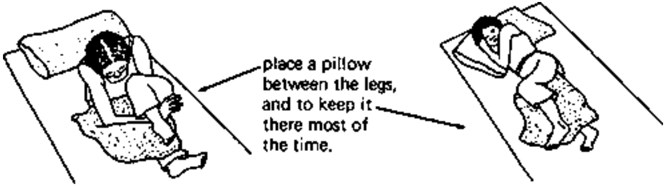


Figure

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.

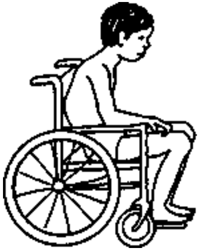
Another common problem for children with spasticity is that the knees pull together and in time contractures prevent the legs from separating. To prevent this, when the child lies on her side she should learn to



Figure

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.

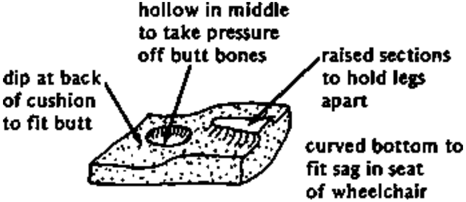


LESS APPROPRIATE

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 butt from sliding forward (and helps prevent pressure sores).



Figure

If possible, make cushion out of ‘micropore’ foam rubber (foam with very tiny bubbles). Rubber-coated coconut fiber also works well.

For more suggestions for wheelchair adaptations, see Chapters 64 and 65.

EARLY PHYSICAL RE-EDUCATION

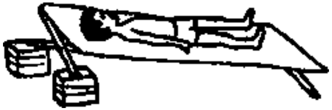
The goal for a spinal cord injured person is to become as independent as possible in doing what he or she wants and needs to do. But even before the skills of daily living are relearned, the person needs to learn to protect the body where functions that used to be

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).**
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.



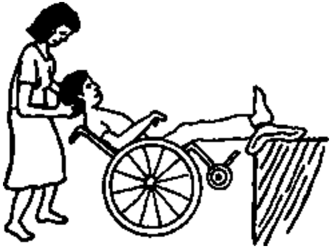
Figure

Start like this for 15 minutes.

In a week or 2 build up to this for 3 hours.

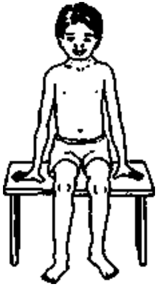
Figure

If the person begins to get dizzy or faint when sitting, tilt him back and lift his feet.



Figure

Lifting exercises help the body relearn to adjust blood pressure - and also prevent bed sores and strengthen arms.



Figure

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

Figure

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.

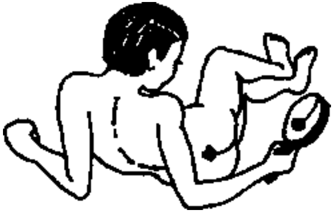
It is important that the child learn to protect himself by changing positions often and

avoiding injuries. This includes:

- **learning to roll over**

Figure

- **turning at least every 4 hours when lying or sleeping**
- **lifting from sitting every 15 minutes**
- **examining the whole body every day for signs of injuries or sores**



Figure

- **washing daily**

Figure

- **learning to protect himself from burns and other injuries. For example,**

DO NOT sit on or touch hot objects (or roads).

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 butt, 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.*

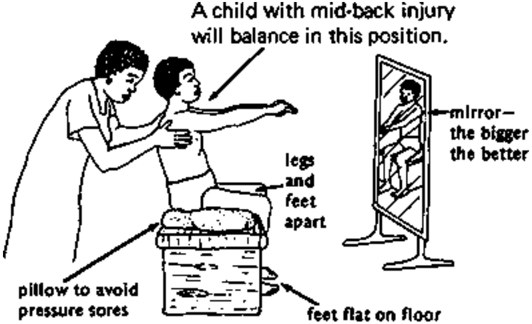
For treatment of specific skin infections (fungus, yeast, bacteria) consult a health worker or a medical book (like *Where There Is No Doctor,* see Chapter 15).

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.**

Figure

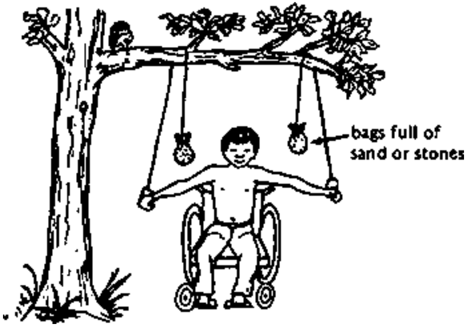


Figure

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.

Weight-lifting is a good exercise to strengthen shoulders.



Figure

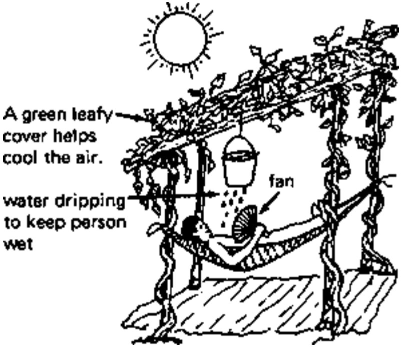
Look for ways to make the exercises useful and fun.

Figure

5. Temperature control Normally, when a person feels hot, he sweats and the blood vessels beneath the skin swell. 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.

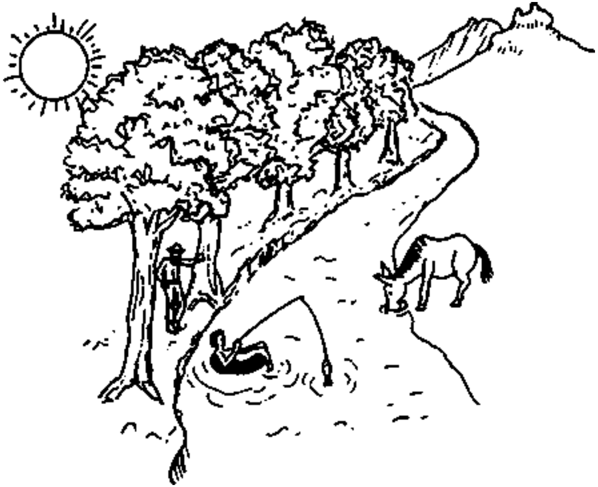
For this reason they must learn (and be allowed) to rest quietly in the shade, in the coolest place possible, during the hottest part of the day



Figure

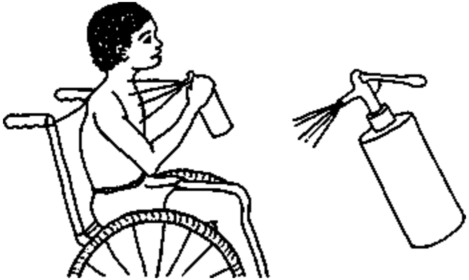
Children with spinal cord injury can learn to paddle around very well in old tire tubes. They love it, and it is excellent arm and shoulder exercise. However, it is very important that someone watches them.

If he can spend part of the hottest hours of the day in a shaded, shallow pool or pond, this is ideal.



Figure

For hot weather, a plastic spray bottle works very well for cooling the body.



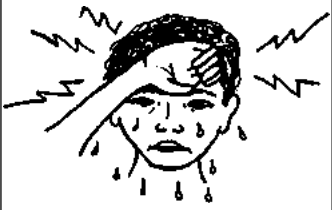
Figure

TAKE CARE also to **protect against cold.** Body temperature can also drop too low.

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	SIGNS (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	• 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) 

	Figure

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. Or take the catheter out. If a catheter is not in place and the person cannot pee, put in a catheter and empty the bladder.**
    - **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.**
    - **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 finger and check if the bowel is packed with hard shit. If it is, put in more lidocaine jelly. Wait 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 as 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 on 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 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,

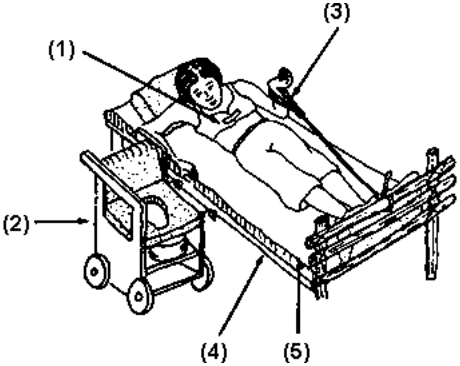
(1) loose-fitting clothing with elastic or easy-to-do fastener (for example, a brassiere that fastens in front)

(2) convertible wheelchair toilet

(3) a rope with a loop for pulling to sit

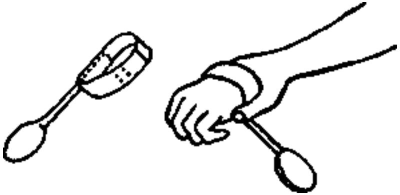
(4) homemade bed, the same height as wheelchair and toilet

(5) padding to prevent sores



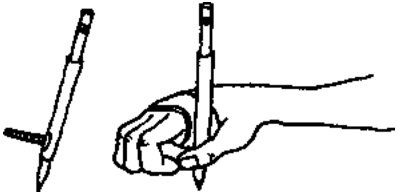
Figure

When hands are affected, devices like these (or others that you can invent) make relearning to eat and write easier.



Figure

‘Velcro’ sticks-to-itself tape makes it possible for the person to put on aids by herself.



metal tube soldered to a piece that fits into hand band

Suggestions for getting in and out of wheelchairs and learning to walk with crutches are included in Chapter 43.

KEEPING ACTIVE

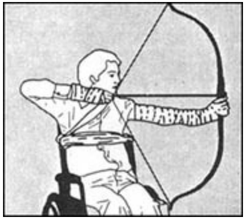
Figure

Many of the ‘complications’ of spinal cord injury happen because the person spends a lot of time just 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.

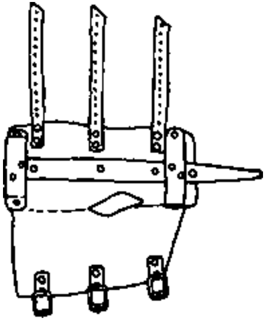
It is important - both for the body and mind - that spinal cord injured persons keep physically active. Let your child do as much for herself as she can: pushing her own wheelchair, bathing, transferring, washing clothes, cleaning house, and helping with work.

Figure

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.



Figure



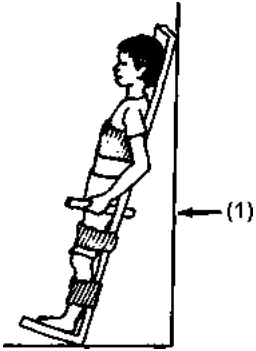
Figure

(*Note:* Archery may also help correct spinal curve. The arm that pulls the string should be on the side with bulge in the back.)

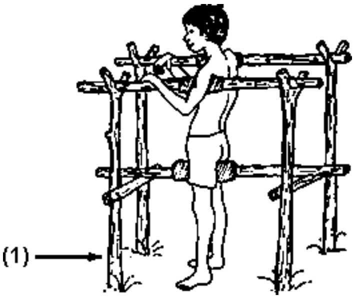
To keep leg bones growing well and to prevent them from becoming weak and breaking easily, even children who may always be wheelchair riders should stand for a while every day. Standing also helps the child's bowels move more often.

This standing frame was invented 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.

This can be done by strapping the child to a 'standing board' (1) or by making some kind of a standing frame.



Figure



Figure

This design for a standing wheel-bed allows a spinal cord injured child with pressure sores on her butt to actively move about. The child can adjust it while on it, from a flat-lying position to a near-standing position. It can be made out of wood or metal.

Figure

Figure

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 2 programs run primarily by spinal cord injured persons are included in Chapter 55. These are the Organization of Disabled Revolutionaries in Nicaragua and the Centre for the Rehabilitation of the Paralysed in Bangladesh. Members of these 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 advice for care of hands and feet without feeling)

Chapter 36 Feeding, especially aids for feeding

Chapter 37 Dressing

Chapter 38 Toilet Training, especially aids

Chapter 39 Bathing

*** Chapter 42 Range-of-motion and Other Exercises**

*** Chapter 43 Crutch Use, Cane Use, and Wheelchair Transfers**

Chapter 51 Adapting Home and Community to Needs of the Disabled

Chapter 52 Growing Up, Social Adjustment, Love, Sex, Role in Family and Community

Chapter 55 Example 3, Centre for the Rehabilitation of the Paralysed, and Example 4, Organization of Disabled Revolutionaries

Chapter 58 Braces

Chapter 63 Walking Aids

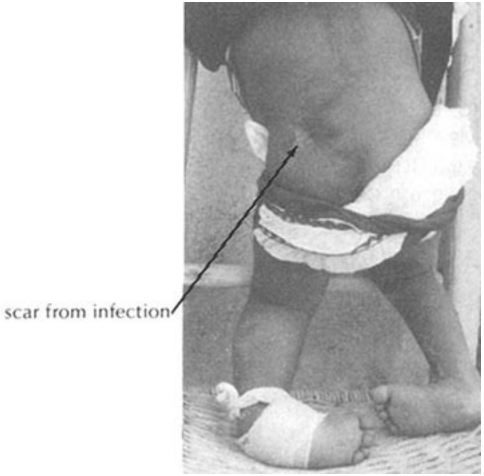
Chapters 64, 65, 66 Wheelchairs

For other references to spinal cord injury, see the INDEX, and the books and reference material.

THE STORY OF JSICA

Jsica 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.



Figure

Misuse of medicines and especially injections is a common and preventable cause of disability. See Chapter 3.

Jsica’s feet became clubbed. When she tried to stand, she developed large, infected pressure sores on her knees and feet.

Figure

When Jsica 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 60).

Figure

They left ‘windows’ in the casts to keep treating the sores.

Figure

Little by little the sores healed and Jsica’s feet straightened. Here one of the workers changes her cast.

Figure

Jsica 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 Jsica's sores. She also assisted Jsica with a 'bowel program', which helps her 'time' her bowel movements. This makes daily activities and going to school much easier.

Vania treats the pressure sore on Jsica's foot.

Here Vania cleans and dresses sores on Jsica’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 Jsica was walking.

With practice Jsica was able to walk with crutches - and finally with only her braces.

Jsica now goes to school in the village. Seeing disabled persons at PROJIMO who were happy, active, and accepted in the community has given Jsica a more hopeful, confident, and adventurous outlook on life.

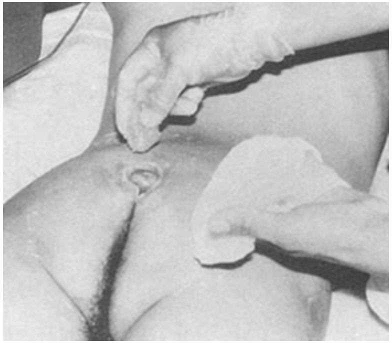
Mari, who is paraplegic, is one of the leaders of the PROJIMO team. Here she works on a cast for making a plastic brace. See her story.

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).

Chapter 24: Pressure Sores

WHAT ARE THEY?

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.

This is a common pressure sore point - over the top of the thigh bone

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.

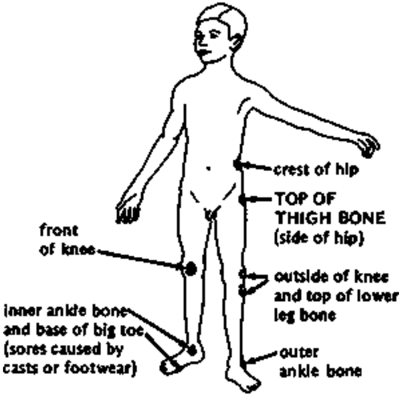
Figure

Where are pressure sores most likely to form?

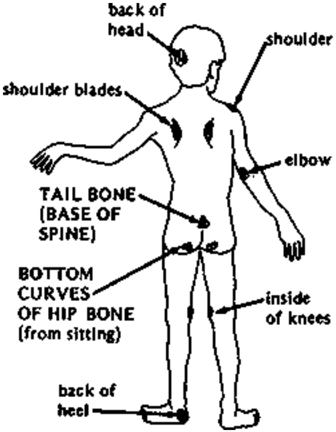
They can form over any bony area. The places where they form most often are shown in the pictures.

The points of highest risk, all on the hips, are marked in CAPITAL LETTERS.

Figure



Figure

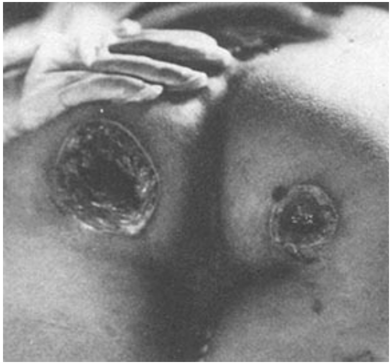


Figure

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.**

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.



These pressure sores in a 15-year-old girl who is quadriplegic were treated with honey and sugar and healed in 2 months. PROJIMO

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), 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.**

- **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.**

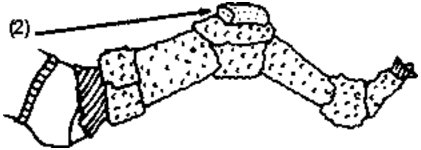
- **Good nutrition is important for preventing pressure sores. Be sure the child gets enough to eat (but do not let her get fat). Give her plenty of fruits, vegetables, and foods with protein (beans, lentils, eggs, meat, fish, and milk products). If the child looks pale, check for signs of anemia and be sure she gets iron-rich foods (meat, eggs, and dark 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" and "Leprosy".**

- **To avoid pressure sores when straightening limbs with casts, put extra padding over bony (2) 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.**



Figure

If it hurts in one of the spots marked with an X, it may be a pressure sore. Remove the cast and see.

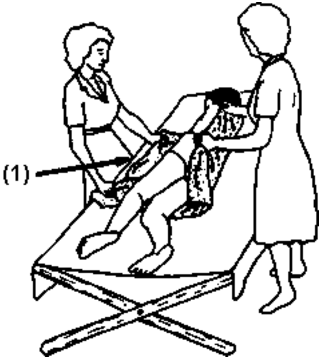
If it hurts in these spots (1), it is probably the tight *cord (tendon).* A little pain is normal with stretching, but if it hurts a lot, examine it.

Figure

Changing positions

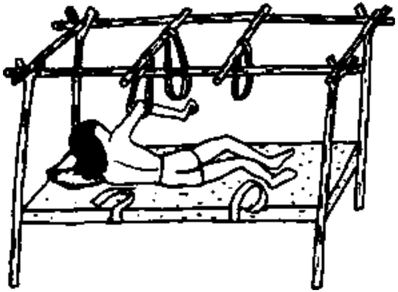
When a child has recently had a spinal cord injury, he must be turned regularly, taking great care not to bend his back.

One good way is to roll him over using a sheet under him, like this (1).



Figure

As the child gets stronger, hang loops and provide other aids, if needed, so she can learn to turn herself.



Figure

At first it is important that the person turn, or be turned, at least every 2 hours, day and night. 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.

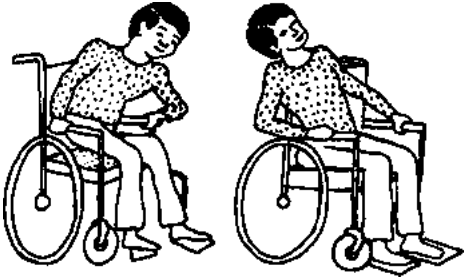
When the child begins to sit or use a wheelchair, there is a new serious danger of pressure sores. The child must get into the habit of taking the pressure off his butt every few minutes.

Juan 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 butt.

Figure

Jos’s arms are weak. He takes the pressure off his butt 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.

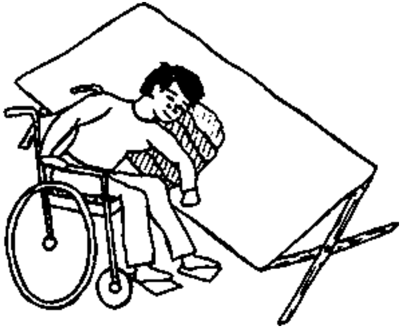


Figure

Carlota has a wheelchair with a low back, so she can lean back and lift her hips off the seat.

Figure

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.

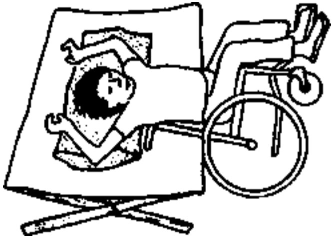


Figure

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 butt.

Figure

Or have someone tip his chair backward for one minute or more. For a longer ‘nap’ that rests the butt, someone can tip his chair backward onto a cot.



Figure

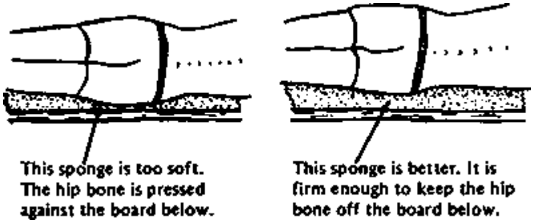
To prevent pressure sores when sitting, take the weight off your butt for one whole minute at least once every 15 minutes!

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.



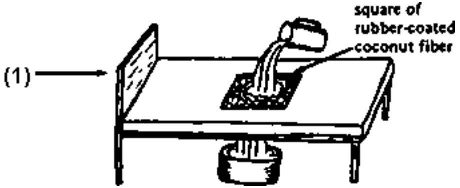
This sponge is too soft. The hip bone is pressed against the board below.

This sponge is better. It is firm enough to keep the hip bone off the board below.

Figure

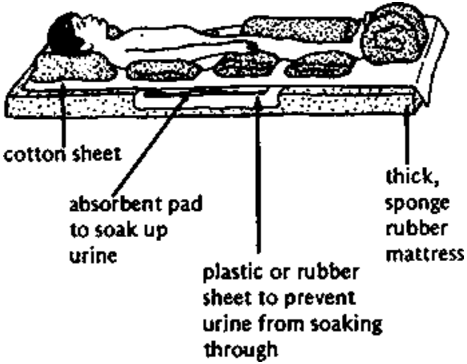
A ‘waterbed’ (bag-like mattress filled with water) or air mattress also works well.

In some countries, an excellent mattress material is made of rubber-coated coconut fiber. Urine can be washed out by pouring water through it (1). 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.



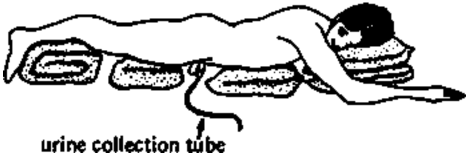
Figure

• 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



BELLY-LYING

Chair and wheelchair cushions

For the child who has lost feeling in his butt, the type of seat cushion he uses is very important - especially if his *paralysis* makes it difficult to lift up or change positions.

Figure

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.

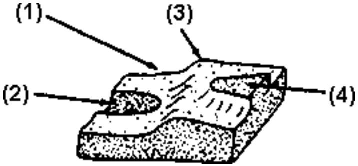
Good cushions can be made of ‘microcell’ rubber, which is fairly firm. It works best if it is cut and shaped to reduce pressure on bony areas:

(1) Dip at back keeps hips from slipping forward.

(2) Hollow in back keeps pressure off butt bones.

(3) Raised ‘shelf’ here puts more pressure under thighs, less on butt. It also helps keep the hips from slipping forward.

(4) A ‘thigh separator’ can be included if needed.



Figure

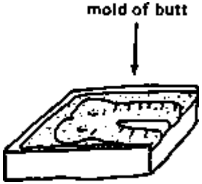
A good, low-cost way to make a fitted cushion is to build a base out of many layers of thick cardboard glued together. Cover it with a 2 or 3 cm. - thick layer of sponge rubber.

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.

Figure

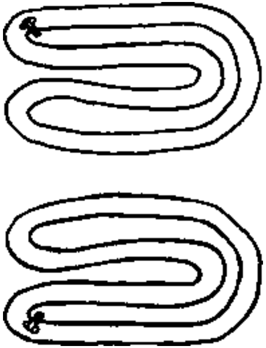
Before making a specially-fitted cushion, you can make a 'mold' of the person's butt by having him sit in a shallow container of soft clay, mud, or plaster. Note the bony hollows and form the seat to fit them.

Figure



Figure

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.

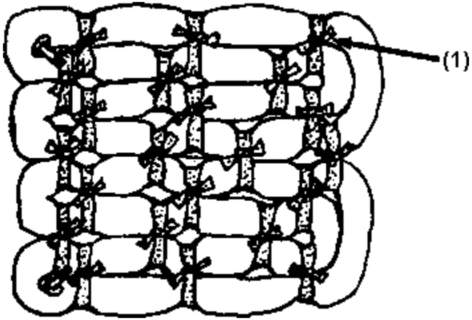


Figure

Bind loops of the tubes together with thin straps of inner tube (1).

Pump in enough air so that the whole butt is held up by air.

(Idea from wheelchair rider-builders at Tahanan Walang Hagdanang (House With No Stairs), Quezon City, Philippines)



Figure

TREATMENT OF PRESSURE SORES

Watch for the first signs of a pressure sore by examining the whole body every day. Teach the child to do this using a mirror.

Figure

If early signs of a sore appear (redness, darkness, swelling, or open skin), change body positions and use padding to protect that area from pressure.

For larger areas (like the bones near the base of the spine), you can try using a small (motor scooter) inner tube to keep weight off the sore area. Put a towel over the tube to

soak up sweat. (Sweaty skin against the rubber can also cause sores.)

Figure

***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.

Figure

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, meat, fish, milk products.**

- Do not rub or massage areas where pressure sores might be forming. This could tear weakened flesh and make the sore inside bigger.

This paraplegic young man has a large pressure sore on his butt. Until it heals, he must not sit. Village rehabilitation workers made this wheel lying cart for him to move about on. Here he helps a boy learn to walk. (Photo, John Fago.)

IF A SORE IS DEEP AND HAS A LOT OF DEAD FLESH:

- 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. Use liquid surgical soap if possible. Then rinse with clean (boiled and cooled) water.

Figure

A large plastic or glass syringe works well for washing out the sore. Wash the syringe well with soap and water after each use.

Figure

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, 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. (See *WTND*)**
- **Follow the advice of an experienced health 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.)

Two folk treatments that help in curing pressure sores

PAPAYA (PAW PAW)

Figure

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 in 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 America, doctors shave thin pieces off blocks of raw sugar and put these into the sore.

Chapter 25: Urine and Bowel Management: 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 peeing and shitting). 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 children should be able to do it themselves. This will help them feel more self-reliant.

URINE MANAGEMENT

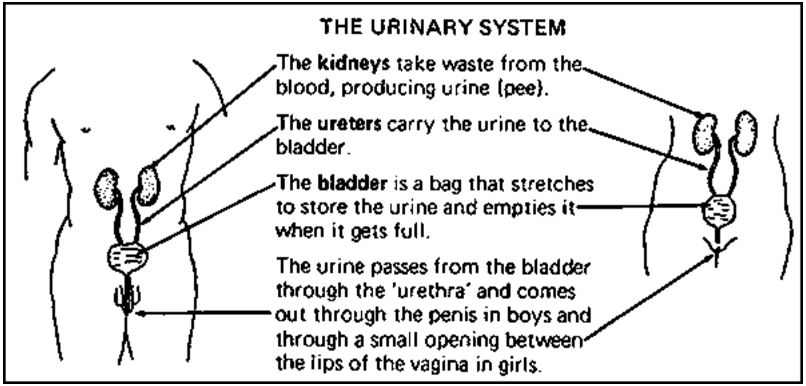
The main goals of urine management are:

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.



Figure

‘Types’ Of bladder - in persons whose feeling and control have been partly or completely lost.

AUTOMATIC 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 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 chance of infection.

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) usually develop automatic bladders. In persons with lower back injuries, the bladder usually stays limp.

During the first weeks, usually a 'Foley catheter' is kept in the bladder all the time. However, after about 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.

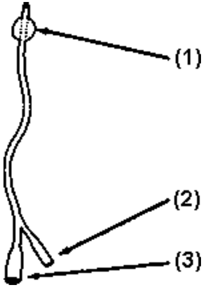
A **catheter** is a flexible rubber tube used for draining urine out of the bladder.

Standard catheter

A 'Foley' catheter has a small balloon near the tip (1). 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 (2).

Urine drains out here (3).



Foley catheter

Methods for automatic bladder

1. TRIGGERING: This method usually causes the bladder-emptying reflex to work when the person is ready to pee. 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.

Figure

- **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.

CAUTION: If you drink more liquid than usual, put in the catheter more frequently to keep the bladder from stretching too much.

Figure

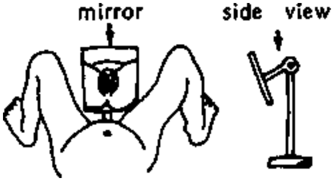
Note: To reduce risk of urinary infections, regular frequent use of the catheter is more important than using a sterile catheter. It is a mistake to stop using the catheter only because you don’t have a chance to boil it (for example, when traveling, or at school). Just wash out the catheter with clean drinkable water after use, and keep it in a clean jar or towel. Do not go too long without catheterizing, and do not stop catheterizing altogether. It is important for your bladder not to interrupt your program.

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.

***Note:* The best catheter size is usually from #8 or #10 for a small child to #14 or #16 for a large child.**

Children as young as age 5 can learn to catheterize themselves



A mirror can help girls to find the urine hole

Note: The great care with cleanliness shown here (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). Wash the catheter well with clean water after each use and keep it in a clean container. Wash your hands well before using it.

1. If possible boil the catheter (and any syringe or instrument you may be using) for 15 minutes, or at least wash them well and keep them clean.

Figure

2. Bathe well (at least daily). Wash well under foreskin or between vaginal lips and surrounding areas.

Figure

3. Wash hands with soap. After washing touch only things that are sterile or very clean.

Figure

4. Put very clean cloths under and around the area.

Figure

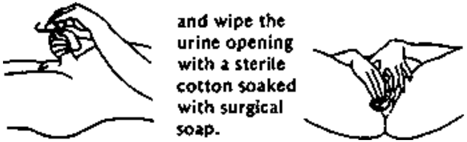
5. Put on sterile gloves-or rub hands well with alcohol or surgical soap.

Figure

6. Cover the catheter with a lubricant (slippery cream) like *K-Y Jelly* that dissolves in water (not oil or *Vaseline*).

Figure

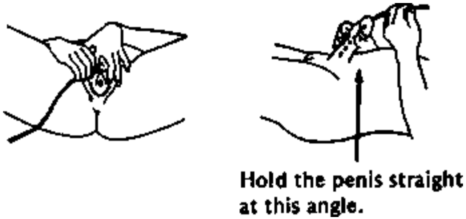
7. Pull back foreskin or open the vaginal lips,



and wipe the urine opening with a sterile cotton soaked with surgical soap.

Figure

8. Holding the lips open or the foreskin back, gently put the catheter into the urine hole. Twist it as necessary but DO NOT FORCE IT.



Figure

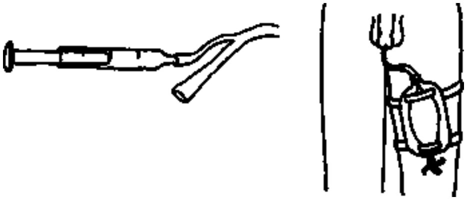
9. Push the catheter in until urine starts coming out - then 3 cm. more.

Figure

10A. If using a regular catheter, each time you pee 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).



Figure

To avoid infections when using a catheter, it is important to be very clean and to use only a catheter that is sterile, boiled, or very clean.

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 high risk of infection.
- Continuous bladder irritation can cause bladder stones to form.
- The catheter may 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)* and water 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.**

- **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 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.**

- **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.**

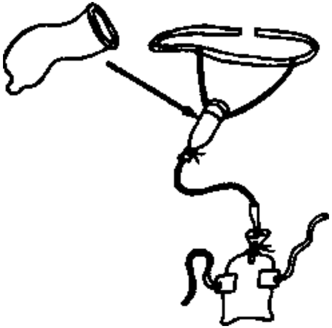
- **If the catheter gets plugged up, take it out, squirt boiled water through it, and put it back. Or use a new one. In emergencies, you can squirt a little (cool) boiled water back through the catheter while it is in place. Use a sterile or very clean syringe.**

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.

condom catheter

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.



regular condom

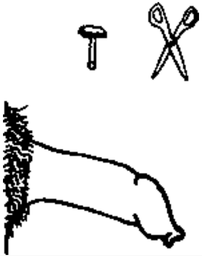
Or a thin, very clean plastic bag can be used. Or, on a child, use the finger of a rubber glove (or a ‘fingercot’).

polyethyene bag

Figure

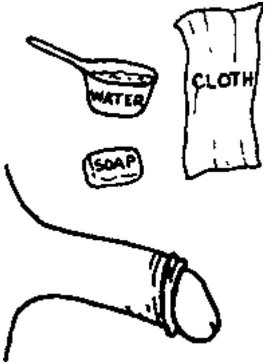
To hold the condom on the penis, a special very stretchy adhesive tape can be used as shown in this series of drawings.

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.



Figure

2. Pull back skin. Wash with soap and water and dry well.

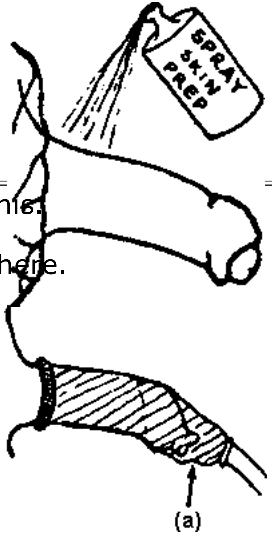


Figure

3. Apply ‘skin prep’ (tincture of benzoin) to help condom stick to skin.

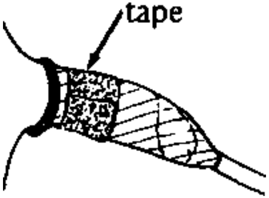
4. Pull foreskin forward over head of penis.

(a) Roll on condom leaving some space here.



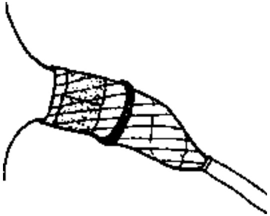
Figure

5. Loosely wrap *Con-stay* tape around condom so it sticks to itself.



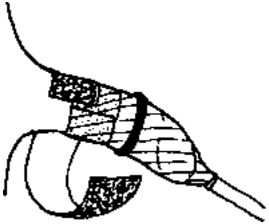
Figure

6. Roll the condom back over the tape.



Figure

7. Add a second strip of tape, ½ on the condom and ½ on the skin.



Figure

8. Cut off the rubber rim.

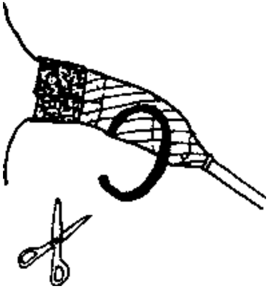
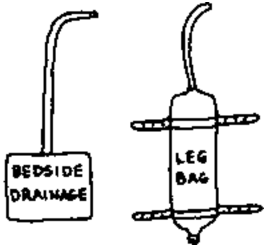
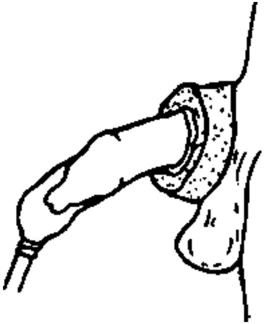


Figure
9. Connect condom to leg bag.    **Figure**

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.

Figure

The ring can be used again and again. So can the condoms if they are carefully washed.



Figure

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.**
- **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.**

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.

2. A Foley catheter can be used, but may lead to problems.

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.

Girls:

1. They can use a Foley catheter. This is often the simplest method, but can lead to urinary infections.

2. Or 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 sanitary pad to catch the urine. Change them often and wash often to protect the skin and prevent sores.

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.

Figure

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.

Figure

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 (see the bottom of the next page); 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 pees. 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 signs that might mean that he has an infection.

Possible urinary signs	**Possible other signs**
• cloudy urine, possibly with pieces of mucus, pus, or blood specks	• body aches
	• general discomfort

- 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)
- increased muscle spasms
- fever
- dysreflexia (headache, goosebumps when sweating, high blood pressure)

Treatment

At the first signs of infection, drink even more water than usual. *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, try one of the medicines in 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.**
- **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.**

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 ***(Gantrisin)***	up to 5 years	500 mg.	4 times
		5 to 10 years	750 mg.	a day
		over 10 years	1000 mg.	
	B. Nitrofurantoin ***(Furadantin, Macrodantin)***	up to 5 years	25 mg.	4 times
		over 6 years	50 mg.	a day
Group 2	A. Ampicillin (many brands)	up to 4 years	125 mg.	4 times
		4 to 8	250 mg.	a day

		years		
		over 8 years	500 mg.	
	Caution*:* Do not use for persons allergic to penicillin			
	B.* Sulfamethoxazole 400 mg. with trimethoprim 80 mg. ***(Bactrim*** or ***Septra)***	up to 4 years	½ tablet	
		4 to 9 years	1 tablet	2 times
		9 to 12 years	1½ tablets	a day
		over 12 years	2 tablets	
	Note*:* This medicine also comes in double strength ***(Bactrim DS and Septra DS).*** Adjust doses if using double strength.			
	C. Cephalexin ***(Keflex)*** or a similar ‘cephalosporin’	up to 5 years	125 mg.	4 times
		over 5 years	250 mg.	a day
Group 3	A. Carbenicillin ***(Geocillin)***	up to 6 years	¼ tablet	4 times
		6 to 10 years	½ tablet	a day
		over 10 years	1 tablet (382 mg.)	
	Note*:* Take 1 hour before or 2 hours after eating.			

	B. Tetracycline (many brands)	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.				

PREVENTION OF URINARY INFECTIONS

To prevent urinary infections, drink LOTS OF WATER

- **Drink lots of liquid - adults, at least 2 liters (8 glasses) a day.**
- **Eat apples, grapes, or cranberries - 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 catheter without boiling it, than not to put it in. If infections are common, catheterize more often.**

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 or shit). 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 or dysreflexia. It is therefore important to prevent serious constipation:

- Drink lots of water.
- Eat foods high in fiber (such as bran, whole grain cereals, fruits, vegetables, cassava, beans, nuts).
- 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 Jsica)

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 (asshole) 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

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 glycerin. These are bullet-shaped pills that are pushed into the anus. They stimulate the bowel and cause it to push out the stool (shit).

suppository

- **Start with a suppository if available. With a finger covered with a glove or plastic bag, and then oil, 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.)**
- **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 butt and anus well and wash your hands.**

PROGRAM FOR A LIMP BOWEL

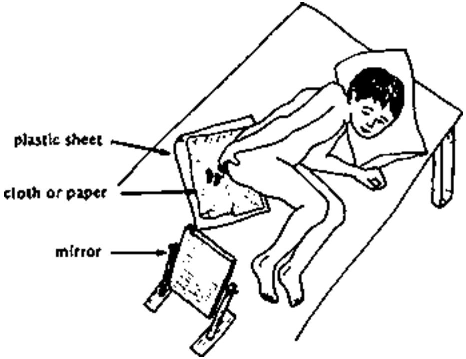
Since the bowel does not push, the stool must be taken out with a finger. It is best done after each meal, or at least once a day.

- **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).**

A thin rubber glove or 'fingercot' (1) helps keep the finger clean.

Figure

If possible, have the child lie on his left side.



Children can learn to do their own 'bowel program'.

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 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 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! If there is dark, old blood and the stools are black and tar-like, seek medical advice.**

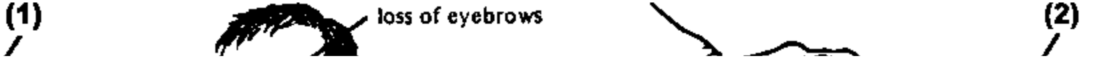
- **A small amount of liquid stool (diarrhea) may be a sign of 'impaction' (a ball of hard stool stuck in the gut). Only liquid can leak around it. Do not give medicine to stop diarrhea; this could make the impaction worse. Try to get it out with a finger.**

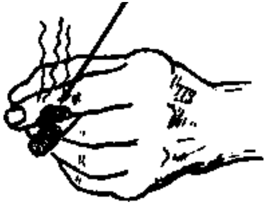
A bowel program may at first seem difficult and messy. But it soon becomes an easy habit. It is very important both for the person's health and his social well-being. Start now, do it regularly at the same hour, and DO NOT MISS A DAY.

Chapter 26: Leprosy: Hansen's Disease

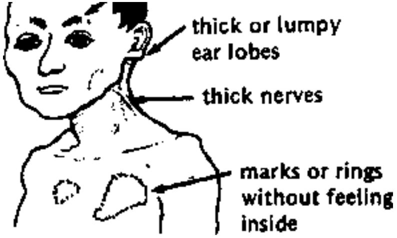
What is leprosy? It is an *infectious* disease that develops very slowly. It is caused by germs (bacilli) that affect mostly the skin and *nerves.* It can cause a variety of skin problems, loss of feeling, and *paralysis* of the hands and feet:

loss of feeling (1) (burns and scars)	deformities of hands and feet	painless ulcers of the feet (2)





Figure



Figure

Figure

Figure

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. Most 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.

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 ever 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, when their leprosy is first diagnosed, can no longer spread it.) However, treatment in some persons must be continued for years 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

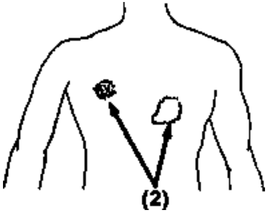
In areas where leprosy is common, health and *rehabilitation* workers should work together with parents and schoolteachers to check all children regularly for early signs of leprosy. Most important are regular checkups of children in homes where persons are known to have leprosy. Checkups should be done every 6 to 12 months and should be continued for at least 3 years.

EARLY SIGNS	WHAT TO LOOK FOR
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	Examine the whole body for **skin patches,** especially the face, arms, back, butt, and legs.

leprosy are never completely white, and are not scaly, except during a reaction)

Figure

If you find a slightly pale patch (1) 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.)



Figure

ringworm-like patches (2), with or without raised border

Note: In early skin patches, feeling is often normal, or nearly so. **If feeling is clearly reduced inside a patch, leprosy is almost certain**

LATER SIGNS

1. Tingling, numbness, or some loss of feeling in the hands and feet.

Or definite loss

TEST INSIDE THE SKIN PATCHES FOR REDUCED FEELING.

of feeling in skin patches.

Figure

(1) With 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.

(2) Thread tied to stick

If the child cannot feel the thread, try pricking lightly with a sterile needle.

Figure

In a similar way, test for a numbness or reduced feeling in the hands and feet.

WARNING: Sterilize the needle in a flame before testing another child.

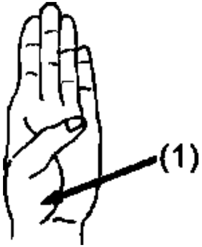
2. Slight weakness or deformity in the hands and feet.

(1) drop foot (Child cannot raise it.)

(2) weakness or clawing of toes.

Have the child straighten her fingers. If she cannot do this, it may be a sign of paralysis from leprosy.

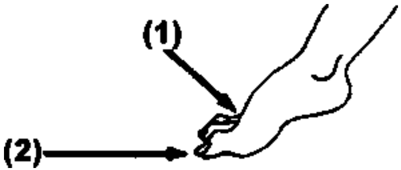
Also have the child try to touch the base of her little finger with her thumb.



Figure

(1) *Muscle* weakness here makes this movement difficult

and may be a sign.



Figure

Figure

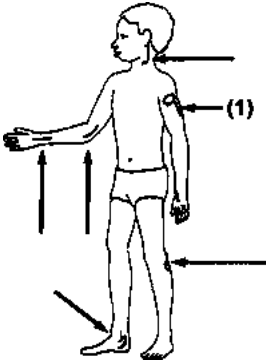
Figure

(*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.

thickening nerve below the ear (From A Manual of Leprosy)

Check for large nerves in these places.



Figure

(1) Also check for large nerves in or near skin patches.

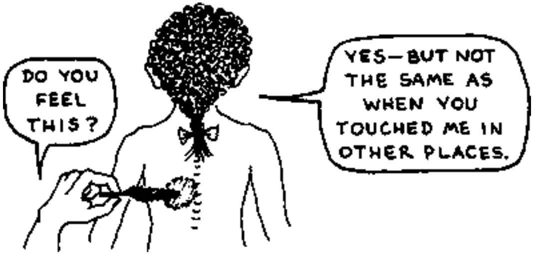
Diagnosing leprosy

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:

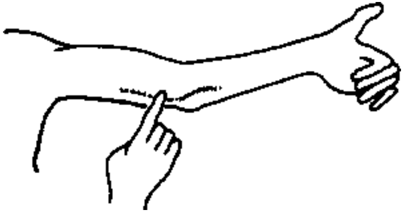
1. definite loss or change of feeling in skin patches



Figure

***Note:* Leprosy patches on face often do not lose feeling as much as on other parts of the body.**

2. definite enlargement of nerves

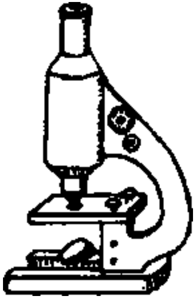


Figure

(For nerves to check)

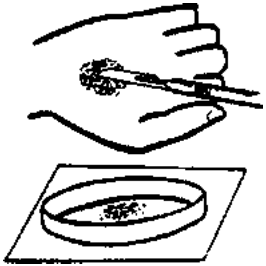
3. presence of leprosy bacilli in a 'skin smear'

A 'split skin smear' is prepared by cutting a thin layer of skin from a skin patch. Less commonly it is taken from the moist skin deep inside the nose - an area that is often heavily infected. The skin sample is placed on a glass slide, colored with special stains, and examined with a microscope.

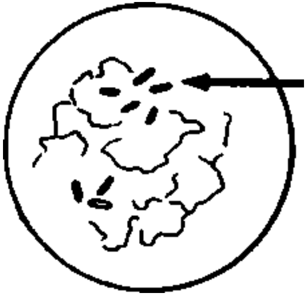


Figure

The bacteria (bacilli) of leprosy, if present, can be seen under the microscope.



taking a ‘split skin smear’ from a skin patch



leprosy bacilli as seen in the microscope

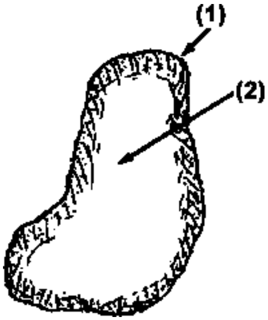
Whenever you suspect leprosy but the diagnosis is uncertain, a ‘skin smear’ should be taken (by a trained worker).

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.

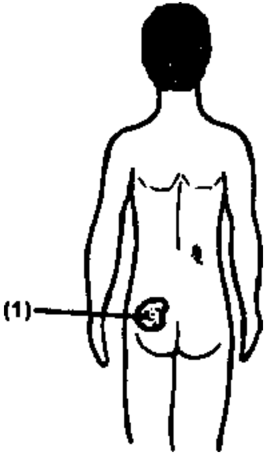
Types of leprosy

Depending on how much natural resistance a person has, leprosy appears in different

types. Here are the characteristics of the main types.

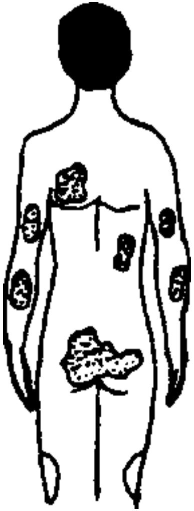
TUBERCULOID LEPROSY (TT) • **in persons with relatively high resistance** • no bacilli in skin smear • Person cannot pass leprosy on to others. • Skin patches are few. They may be very variable in appearance, but often have raised margins and (1) and flat centers (2)  **Figure** • Feeling is usually reduced or absent in	**'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	**LEPROMATOUS LEPROSY (LL)** • **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.

centers of the skin patches. (1)



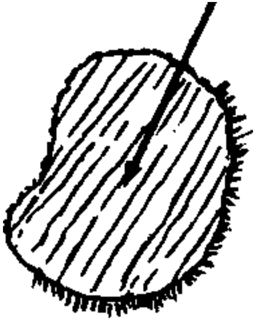
Figure

- 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. When it does, it often happens early and causes loss of feeling or strength in **only one hand**



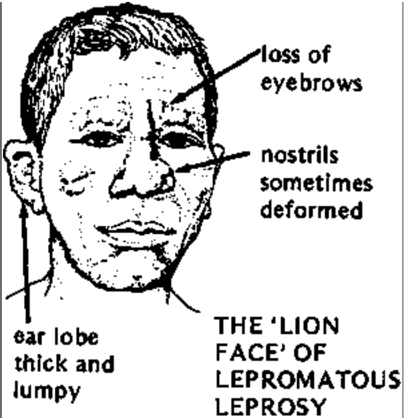
Figure

- Borderline leprosy may suddenly shift toward one or the other extreme. When these shifts occur, 'leprosy reactions' are especially likely to appear.
- Severe nerve damage often results, with loss of feeling and loss of strength in both hands and **both** feet, with deformities.



Figure

- The skin of the face may become thick, lumpy, reddish, especially over the eyebrows, cheeks, nose, and ears.

or foot. • Usually responds quickly to treatment because the body helps fight the disease.	 **Figure** 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).	 **Figure** • 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

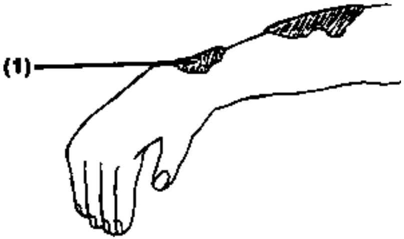
Sometimes persons with leprosy have sudden periods of increased problems. These may be something like an allergic reaction to the leprosy bacilli. Leprosy reactions can happen in untreated persons, during treatment, or after treatment has stopped. Reactions can occur when there are changes in the body, 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 (1)**
- **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.)**



Figure

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, breasts, 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)

NORMAL EYE

EYE WITH IRITIS

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.

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 with DDS, rifampin probably needs to be given only once a month. This reduces both cost and side effects.

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 leprosy control program. Usually it is wise to cooperate with these programs instead of trying to treat leprosy by yourself.

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 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, 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.

Chloroquine (a medicine for malaria) is also effective. To adults, give 2 tablets of 250 mg. 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.

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. Very carefully pad splints for hands or feet that do not feel pain.

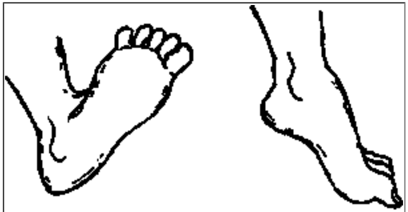
A good splint for the hand - to avoid contractures and maintain a useful position.

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 42.)

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
	leads to →		leads to →	 **scarring and blindness**

Eyes do not blink normally		 **eye irritation and infection**		
 **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;**	leads to →	 **painless sores and injuries** stiffness and contractures;	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

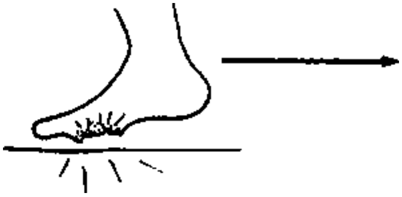
When there are level 1 problems, there is a lifelong danger of level 2 and 3 problems. Because feeling has been lost, the person no longer protects herself automatically against cuts, sores, thorns, and other injuries. And because they do not hurt, these injuries are often neglected.

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.

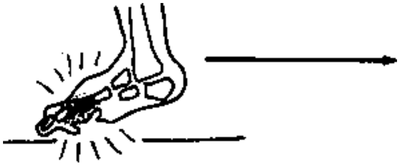
Figure

So he keeps walking until the blister bursts and becomes infected.



Figure

Still without pain, the infection gets deeper and attacks the bone.



Figure

In time the bon destroyed and t becomes more a deformed.

Figu

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

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.**

Figure

- **Close the eyes tightly often during the day, especially when dust blows.**
- **Roll the eyeballs up as you try to close eyes tight.**

Figure

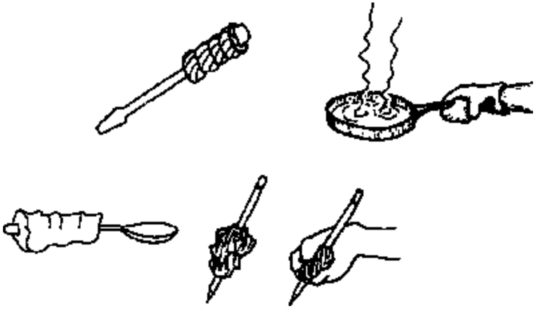
- **Keep eyes clean. Wash well around eyes, keep flies and dirty hands away.**

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, wide 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.

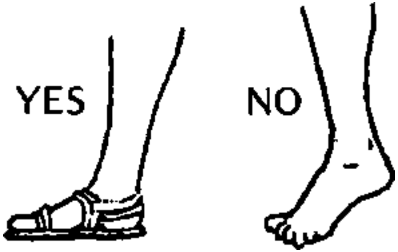


Figure

For more aids for gripping.

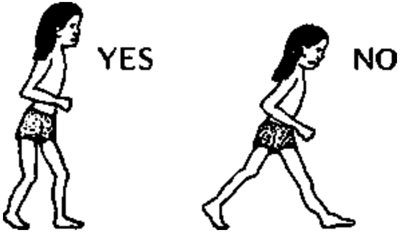
Feet:

- **Avoid going barefoot. Use shoes or sandals. (For suggestions on appropriate footwear, see the next page.)**



Figure

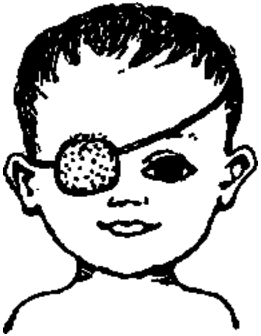
- **Learn to take short steps.
This helps protect the feet.**



Figure

INJURY CARE

Eyes: Close eyes often. If necessary, use a simple eye patch. If eye gets infected (forms pus) use an antibiotic eye ointment. Put the ointment into lower lid without touching the eye.



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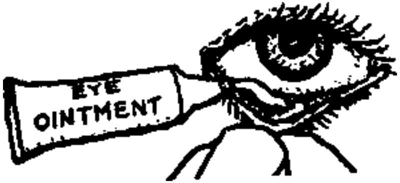


Figure

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 every day

- **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.**

Figure

- **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).**

Figure

- **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.

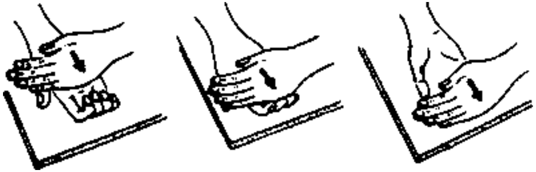
PREVENTION of contractures and deformities in persons with paralysis

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. However, loss of feeling makes prevention more difficult.

Exercises to maintain full range of motion are covered in Chapter 42.

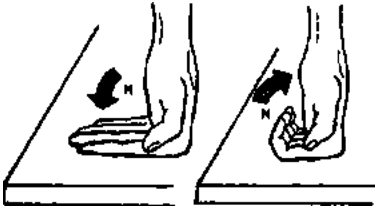
- **Exercises to prevent fixed clawing of the hands can be done by ...**

... gently straightening the fingers like this:



Figure

and like this:



Figure

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

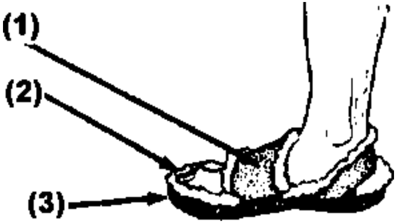
- **A good exercise to prevent ‘tiptoe’ contractures with ‘foot drop’ is to stretch the heel *cords* by leaning forward against a wall or by squatting with heels on the ground.**

Figure

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). (1)**
- **a soft innersole about 1 cm. thick.(2)**
- **a tough under-sole so thorns, nails, and sharp rocks do not injure foot.(3)**
- **Footwear should be acceptable (not look too strange or unusual) so that the person will use it.**



Figure

AVOID:

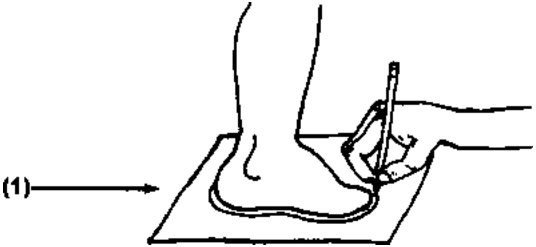
- plastic shoes or sandals
- soft-soled sandals or thongs that thorns can pass through
- using nails to fasten heels and soles (These might poke through and injure the foot. Better to sew on soles or use glue.)

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. (1)

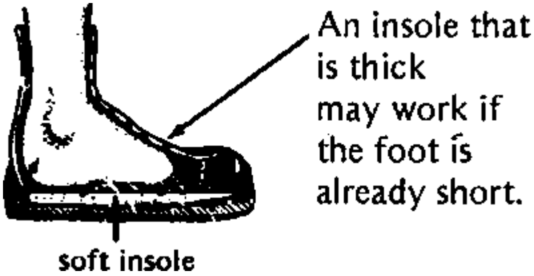


Figure

- **Check the market. You may find a canvas shoe or tennis shoe that already has a good insole.**

Figure

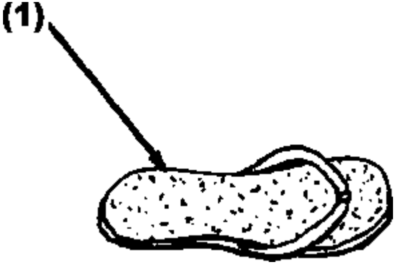
- **Or you can put soft insoles into the shoes. But *CAUTION:* If you put an insole that is thick into a standard shoe, there may not be enough room for the toes - unless you cut out the part over the toes and leave them open.**



Figure

- **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. (1)

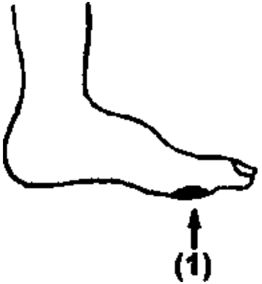


Figure

For the under-sole you can use a piece of old car tire.

Figure

- **For persons who have developed sores on their foot here (1), a bar here (2) or a foot (3) support here may help take pressure off the ball of the foot and prevent new sores.**



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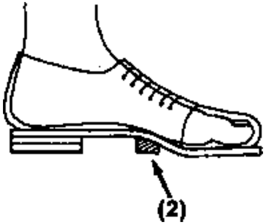

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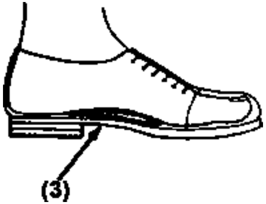
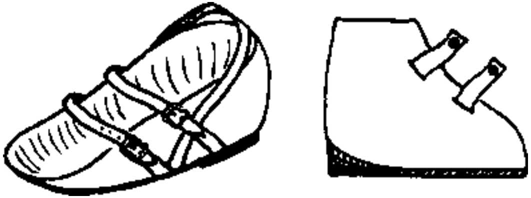


Figure

- **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*.**



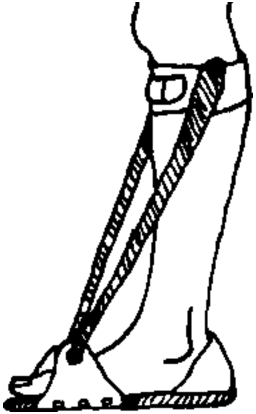
Figure

- **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.

Or make a simple device to hold the foot up.

Figure



Figure

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. 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 47) 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. (Organizations 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 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 an arm or leg because of accidents. Or

limbs must be cut off because of advanced bone *infections* or dangerous tumors (cancer).

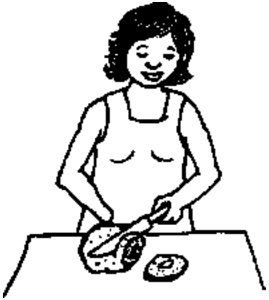
Deciding what to do for a child with an amputation depends on a number of things, including the age of the child at the time of amputation, the amount of amputation, and above all, what the child (and parents) want and accept.

MISSING BOTH HANDS (any age)  **Figure**	He will probably want and accept hooks, or whatever can help him hold things better.  **Figure**	Until he can get gripping hooks, figure out ways to attach tools and utensils to his stumps so he can do more for himself.  **Figure**	A child with high arm amputations from birth often learns to use his feet almost as well as his hands.  **Figure**
MISSING ONE HAND	If she was born that way and is given an artificial limb early, she will usually accept	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

Figure

it and keep using it.

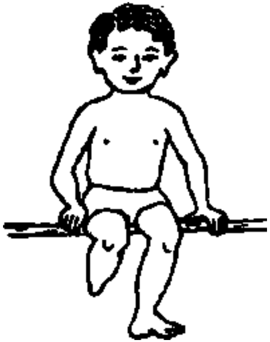
Figure



Figure

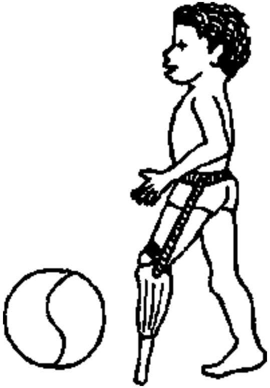
made for her.

AN AMPUTATION BELOW THE KNEE (one or both legs)



Figure

He should get an artificial leg as soon after the amputation as possible - or by one year: of age.



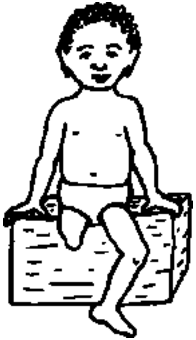
A growing child will often need a new, larger limb. Therefore, try to fit him with low-cost limbs that are easy to replace.

Figure

Limbs with detachable feet - although often expensive - can be lengthened.

Figure

Figure

ONE LEG AMPUTATED ABOVE THE KNEE  **Figure**	Up to age 10 (or more) she can walk well with a straight leg (no knee joint).  **Figure**	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).  **Figure**	
BOTH LEGS	When very young, he	When older, he may prefer longer	Children with very

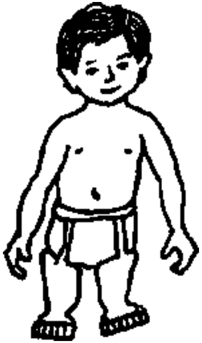
BOTH LEGS AMPUTATED ABOVE THE KNEES

When very young, he may move about most easily on short ‘stump’ limbs.

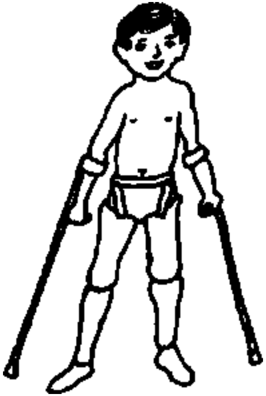
When older, he may prefer longer limbs that make him as tall as other children-even if this means using crutches.

Children with very high amputation of the legs may do best in wheelchairs.

Figure



Figure



Figure

CARE OF THE AMPUTATED LIMB

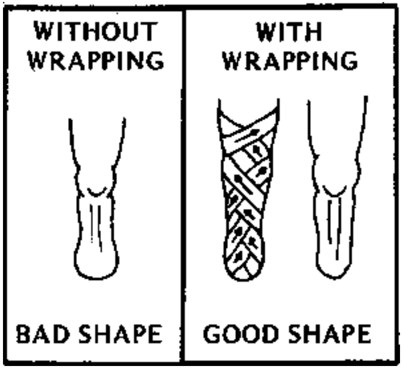
The goals in caring for the stump are to maintain a good shape and good position for fitting an artificial limb. This means taking active steps to:

1. **avoid swelling,**
2. **keep the full range of motion (prevent *contractures),* and**
3. **maintain strength.**

WRAPPING THE STUMP

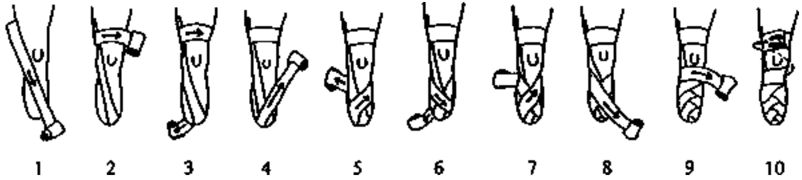
To prevent swelling and keep a good shape for fitting an artificial limb, it is important to wrap the newly amputated limb for a long time after it has been cut off.

The leg should be wrapped in a way that squeezes the liquid in the leg upward (rather than trapping it at the end). Use an elastic bandage in this manner:



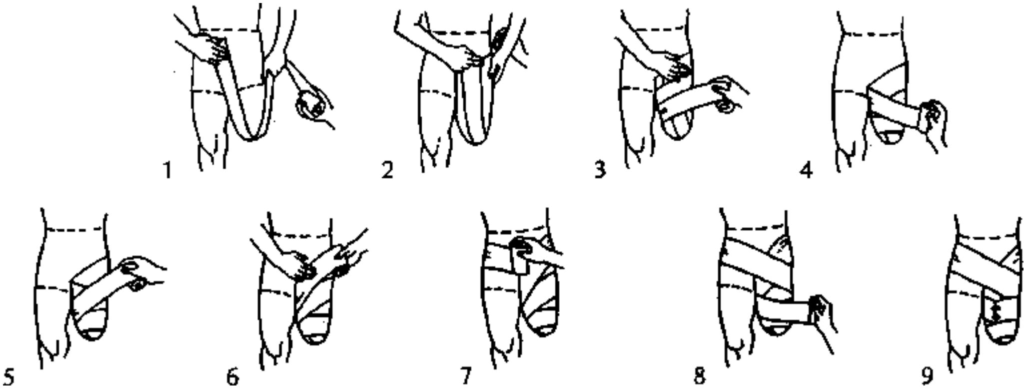
Figure

Below knee



Figure

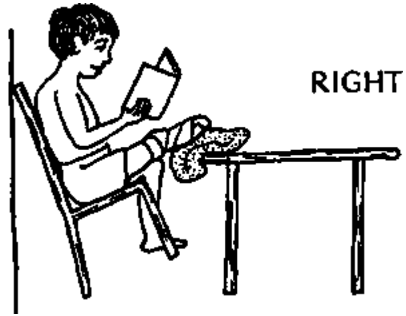
Above knee



Figure

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.



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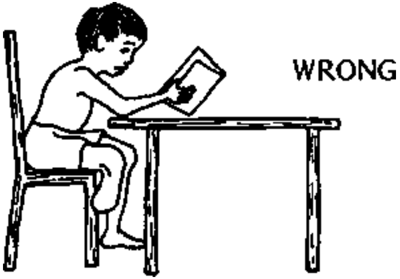


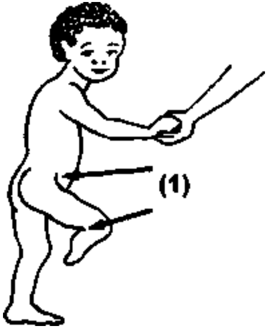
Figure

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.

Contractures here and here will need to be straightened before this child can be fitted with a limb. (1)

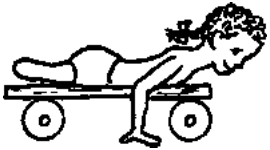


Figure

POSITIONS

Encourage positions that keep the joints stretched, and avoid those that keep the joint bent.

CORRECT



Figure

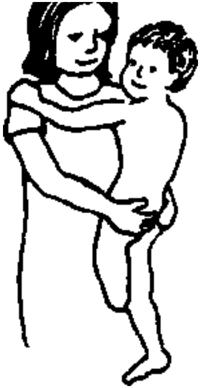
CORRECT

Figure

WRONG

Figure

CORRECT

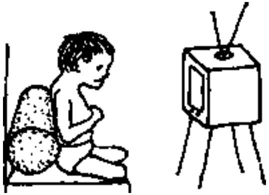


Figure

WRONG

WRONG

CORRECT

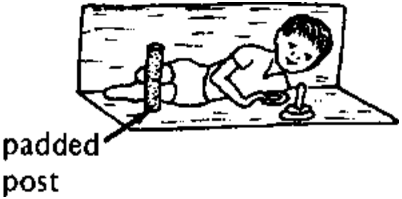


Figure

ONLY WHEN NECESSARY FOR MOVING ABOUT

Figure

BETTER
(But it can still cause hip contractures.)



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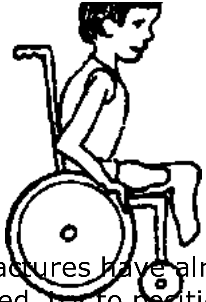
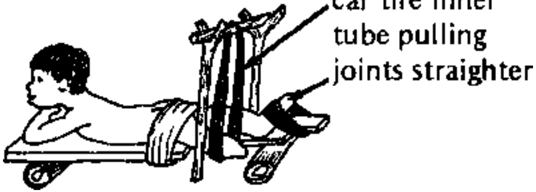
CORRECT



If contractures have already developed, try to position the child in ways that stretch them.

Figure



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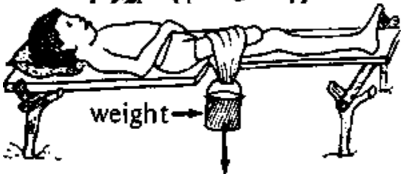
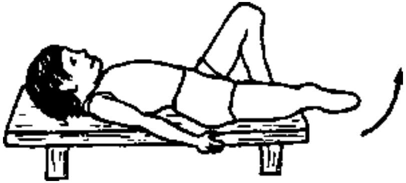


Figure

STRETCHING EXERCISES

Figure



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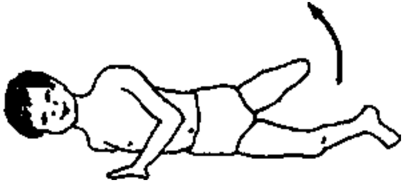
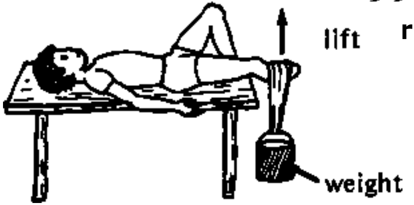


Figure

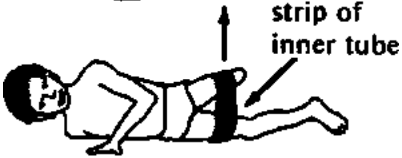
STRENGTHENING EXERCISES

Try to strengthen especially those muscles that straighten the joints, and those muscles needed for walking.



re hips

Figure



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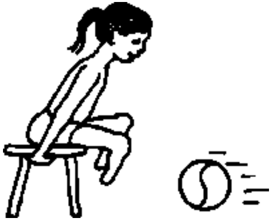
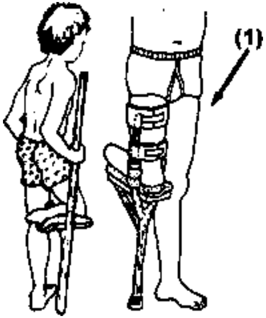


Figure

Figure

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. (1)



Figure

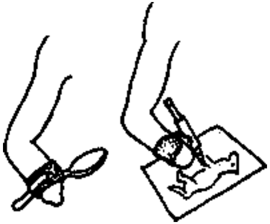
However, it is very important that the child do **stretching and strengthening exercises daily** if he uses a bent-joint aid.

Figure

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 67.

ALTERNATIVES FOR A CHILD WITH AMPUTATED HANDS



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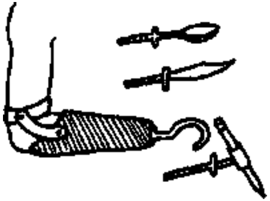


Figure

Figure

Figure

simple tool and

cuff with

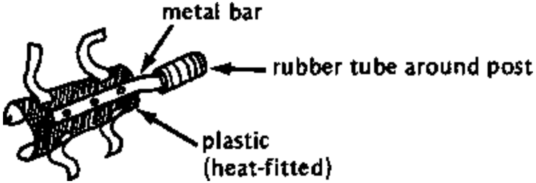
hooks that open and close to grip

surgery that turns

utensil holders made of cloth, leather, or plastic	changeable tips	(operated by movements of shoulders and back)	the 2 bones of the forearm into pinchers
	 **Figure** rubber or wood hand, not for use but for looks	 **Figure** 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.

Child presses stump against post



Figure

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 56, “Making Sure Aids and Procedures Do More Good Than Harm”.

Chapter 28: Burns and Burn Deformities

Serious burns are common in villages where people cook, warm themselves, or sleep by open fires.

First aid for burns is discussed in health care manuals, including *Where There Is No Doctor.* Here we discuss only the precautions that can be taken to help prevent deformities and *disabilities* from burns.

The most common deformities resulting from severe burns are *contractures,* and the scarring, or sticking together, of skin around joints. For example:

Figure

Figure

Figure

Figure

Lupito slept too close to the fire and his blanket caught fire.

He was badly burned under the arm and behind

As he was healing, Lupito lay with his arm and leg bent. This kept the air away from

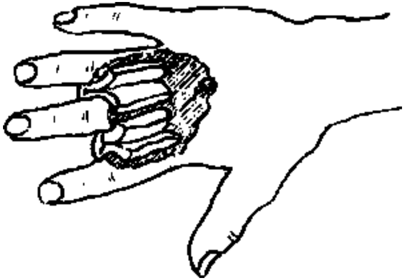
But as a result, the skin scarred to itself. After the burns the knee.

the burns, and they hurt less.

healed, Lupito could not lift or straighten his arm or straighten his leg.

TO PREVENT SCARRING TOGETHER OF THE SKIN AT JOINTS:

Figure



Figure

Figure

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.

TO HELP BURNS HEAL: When possible, leave the burns open to the air.

Protect against flies and dust with mosquito netting or by covering the

To keep the blanket or

burns with light gauze.

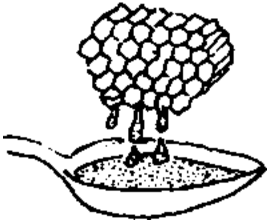
Figure

Figure

mosquito netting off a burned part of the body, cut a cardboard box or make a frame to hold it up.

If burns need to be covered, you can put petroleum jelly *(Vaseline)* on sterile gauze or sterilized cloth and gently cover the burn.

To help healing, and to prevent or control infection of deep or open burns, you can put **bees' honey or sugar** directly on the burn. Or make a paste of bees' honey mixed with sugar. **It is important to wash the burn with water that has been boiled and cooled, and to put on fresh honey 2 or 3 times each day.** (If the honey gets too diluted with oozing from the burn, it will breed germs rather than kill them.)

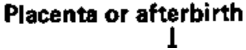


Figure

BEES' HONEY IS EXCELLENT FOR HEALING BURNS AND OPEN SORES

Ways to help burns heal faster and better

Skin grafts



Also, to speed

Large deep burns heal very slowly and form ugly stiff scars. Healing can be faster and scarring reduced by using ‘skin grafts’. A very thin layer of skin from another part of the body is stretched over the burn. Usually this is only done by a surgeon (although some village health workers have been taught how to do it).

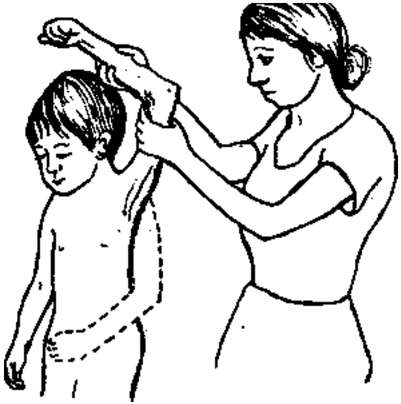
Figure

healthy healing, you can use the fresh ‘bag of waters’ or transparent membrane that comes out with the placenta after childbirth.

This sac must be kept clean. Wash it in boiled and cooled, slightly salted water, and put it on the burn as soon as you take it out of the water.

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.



Figure

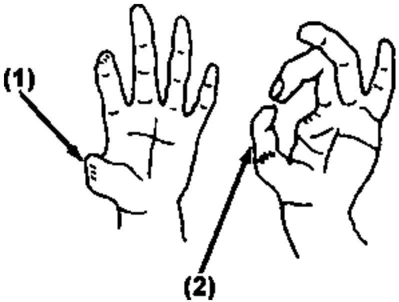
For exercise details, see Chapter 42. If scarring is severe, you may need to continue range-of-motion exercises for years after burns are healed. Scar tissue does not grow and stretch like normal skin. **Skin contractures** often form and may slowly get worse - sometimes even with exercises.

Before beginning exercises, it helps to rub body oil or cooking oil into the healed burn (but never into a fresh burn). Reports from several parts of the world claim that fish oil on healed burns 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.)

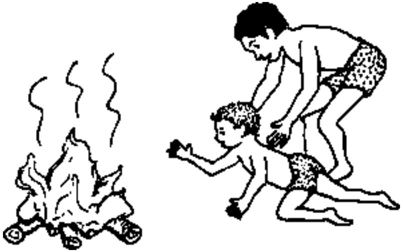


Figure

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. (1)

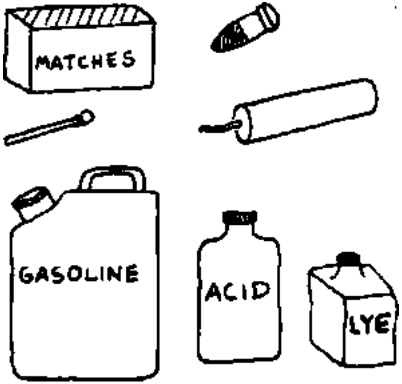
index finger moved to form thumb (2)

PREVENTION of burns is important:



Figure

Keep small children away from fires. Where there are open fires, be sure an older child or someone else watches the young children carefully.



Figure

Keep matches and explosives out of reach of children.

Figure

Turn handles of pans on stove so that the small child does not pull them.

Chapter 29: Fits: Epilepsy

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.

Figure

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. In fact, cerebral palsy and epilepsy**

often occur together. Meningitis 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, malaria of the brain, or poisoning (see *Where There Is No Doctor*). Epilepsy that steadily gets worse, especially if other signs of brain damage begin to appear, may be a sign of a brain tumor (or of hydrocephalus in a baby). 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*).

- **Hereditary. There is a family history of fits in about 1/3 of persons with fits.**

- **Unknown causes. In about 1/3 of epilepsies, no family history or history of brain damage can be found.**

Fever fits. Children who have once had a fit with a high fever often will have fits again when they have a 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 (diarrhea 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,”).

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***).

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***).

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. 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 or 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. However, some children stop having fits after a few months or years.

Usually there is no need to know the exact kind of fits a child has. However, some kinds of fits require different medicines. The chart describes the main types of fits, when they begin, and their treatment.

WHEN ARE SPECIAL MEDICAL STUDIES NEEDED?

In some poor countries, 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.

Usually EEG’s and other costly testing are not helpful.

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 other place where she cannot hurt herself.

- 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, medicine, nor any object to prevent biting the tongue.

- 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. Let her sleep. For headache, which is common after a fit, give acetaminophen (paracetamol) or aspirin.

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.

Figure

A child who often injures his face with fits may need a 'hard hat' helmet with a face mask.

Figure

You can make a 'cage' of stiff wire and wrap it with strips of inner tube, soft cloth, or

Or cut a piece of old car tire something like

Or sew strips of cloth filled

sponge rubber.

Figure

this.

Figure

with
padding.

Figure

MEDICINES TO PREVENT FITS

There are no medicines that 'cure' 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 one year after the last fit. Only then should you gradually lower and stop the medication to see if he still needs it.

CAUTION: Great care is needed to select the medicines that help the individual child most, and which do her the least harm. Try to avoid giving so much medicine that she always seems sleepy, dizzy, slow-moving, or loses interest in things. A few fits may be better than too much medicine -

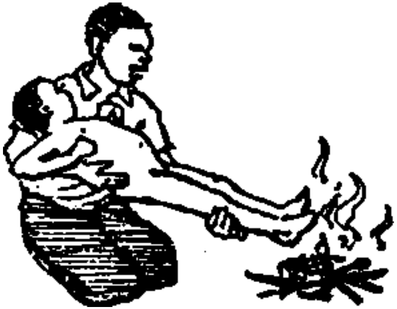
which can poison the child.

Choosing medicines

The best medicine (or medicines) for a child with epilepsy is one that is:

- **effective (prevents the fits).**
- **safe (has few side effects).**
- **cheap (because it must be taken for years).**
- **easy to take (long-acting, few doses a day).**
- **easy to get.**

WARNING: When a child is having a fit **do not put his feet into a fire.** It will not ‘frighten him back to life’ but will severely burn him.



Figure

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 medicines will control the fits completely.

The best medicine to try first for almost all types of fits is usually phenobarbital. Often it is very effective, and is relatively safe, cheap, and easy to take. Its effects last for 24 hours, so that one dose a day is usually enough.

The next best medicine for 'big' fits is usually phenytoin. It is also fairly safe, cheap, and usually needs to be taken only once a day. (For some kinds of epilepsy, however, phenytoin may make fits worse.)

For most epilepsies, phenobarbital and phenytoin are often the best drugs. First try each alone, and if that does not work, try both together. Most other drugs are less likely to be effective, are often less safe, and are much more expensive.

Unfortunately, many doctors prescribe more expensive, less safe, and often less effective medicines before trying phenobarbital or phenytoin. Partly this is due to drug companies that falsely advertise their more expensive products. In some countries, phenobarbital is difficult to get - especially in pill form. The result is that many children's fits are poorly controlled, using drugs that cause severe side effects and that are very costly. *Rehabilitation* workers need to realize this and do what they can to help provide the safest, cheapest medicines that will effectively control each child's fits.

CAUTION: To prevent choking, do not give medicines 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. Never give medicines by mouth to a child while she is having a fit, or while she is asleep or unconscious.

It is usually best to start with only one anti-fit medicine - usually phenobarbital, if available. Start with a low to medium dose, and after a week, if fits are not controlled and

if there are no serious side effects, increase to a higher dose. After a few days, if the fits are still not controlled, add a second medication - usually phenytoin, for 'big fits'. Again, start with a low to medium dose and gradually increase as needed.

CAUTION: When you stop or change a child's medicine, do so gradually. Sudden stopping or changing the medicine may make fits worse. Also, it may take several days for a new medicine to have its full effect.

☠	***WARNING:*** **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.**

INFORMATION ON DOSAGE AND PRECAUTIONS FOR ANTI-FIT MEDICINES

Phenobarbital (phenobarbitone, *Luminal*)

For all types of fits. Usually comes in:

tablets of 15 mg.	
tablets of 30 mg.	(It costs less to buy 100 mg. tablets and cut them into pieces).
tablets of 100 mg.	

Dosage: Because tablet sizes differ, we give the dosage in milligrams (mg.).

The usual dose is 3 to 6 mg. for each kg. of body weight every day (3 to 6 mg./kg./day) - usually given in **2 doses** (morning and evening):

Give 2 doses a day. In each dose give:

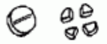
children over 12.....	50 to 150 mg.

children 7 to 12 years...	25 to 50 mg.
children under 7 years...	10 to 25 mg.

SIDE EFFECTS AND COMPLICATIONS

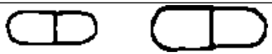
- Too much can cause sleepiness or slow breathing.
- Some very active children become over-active or behave badly.
- Rare side effects include mild dizziness, eye-jerking, and skin rash.
- Bone growth problems may occur - especially in retarded children. Extra vitamin D may help.
- Bitter taste. It may help to grind up the tablet and give it with honey or jam.

- Mildly habit forming.

CAUTION: If tablets of 100 mg. are used, be very sure the family understands that they must be cut into pieces. Show them first and then have them do it.		**Giving a whole tablet instead of a small piece can poison the child.**	

Phenytoin (diphenylhydantoin, *Dilantin*)

For all types of fits ***except*** brief fits that suddenly throw the child out of balance (‘jolt fits’) or ‘minor fits’ with staring, blinking, or fast movement of eyes. (Phenytoin may make these kinds of fits worse.)

Usually comes in:	capsules of 30 mg.	 **Figure**
	capsules of 100 mg.	

	syrup with 125 mg. in each 5 ml. (1 teaspoon)

Dosage: using capsules of 100 mg. 5 to 10 mg./kg./day

Start with the following dose once a day:

children over 12 years..... 100 to 300 mg. (1 to 3 capsules)
children 7 to 12 years...... 100 mg. (1 capsule)
children 6 or under.......... 50 mg. ($^1/_2$ capsule)

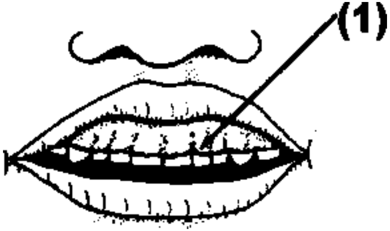
After 2 weeks, if the fits are not completely prevented, the dose can be increased, but not to more than twice the amount.

If child has no fits during several weeks, try lowering the dose little by little until you find the lowest dose that prevents the fits.

SIDE EFFECTS AND COMPLICATIONS

WARNING: Watch for **dizziness, eye-jerking, seeing double,** and **severe sleepiness.** Lower the dose if any of these occur. They are early signs of poisoning, which could cause permanent brain damage.

- **Swelling and abnormal growth of the gums** often occurs with long-time use. It can be partly prevented by good mouth care. **Be sure the child brushes or cleans his teeth and gums well after eating.** If he cannot do it by himself, help him, or better, teach him. If the gum problem is severe, consider changing medicines. (See ***Where There Is No Dentist****.*)



very swollen, sore gums almost covering teeth-caused by not keeping teeth clean while taking phenytoin (1)

- Occasional side effects: increased body hair, rash, loss of appetite, vomiting.
- High dosage may cause liver damage.
- Bone growth problems sometimes occur - especially in retarded children. Extra vitamin D may help.

WARNING: Sudden stopping of phenytoin may cause the child to have a **long-lasting fit.** Therefore, when stopping or changing the medicine, **lower the dosage gradually.**

Carbamazepine *(Tegretol)*

Useful for almost all types of fits as a second choice, or in combination. Especially useful for ‘psychomotor’ fits. High cost is a disadvantage. (Unfortunately, many doctors prescribe it as first choice when cheaper drugs such as phenobarbital or phenytoin are likely to work as well or better.)

Usually comes in: tablets of 200 mg.

Dosage: 14 to 25 mg./kg./day divided into 2 to 4 doses. Start with 20 mg. each day for each kilogram the child weighs. For example, a 30 kg. child 10 years old would start with 600 mg. a day, which she could take in 3 doses, each of 200 mg. - or one tablet 3 times a day.

It is best to **take it with meals.**

The dose of carbamazepine should be adjusted to the individual child. Depending on how well it controls the fits, it can be raised to 30 mg./kg./day (but no higher) or dropped to 10 mg./kg./day.

SIDE EFFECTS AND COMPLICATIONS

- Rarely causes liver damage or reduces ability of blood to clot.

OTHER DRUGS SOMETIMES USED FOR EPILEPSY

- **Primidone *(Mysoline)* For all fits. Start with low doses and gradually increase to 10 to 25 mg./kg./day in 2 to 4 divided doses. May cause sleepiness, dizziness, vomiting, or rash.**

- **Ethosuximide *(Zarontin)* First choice for ‘minor fits’ with blank staring, eye-fluttering, and perhaps strange motions - especially if the fits occur in groups in the morning and evening. Give 10 to 25 mg./kg./day in 1 or 2 doses, with food to avoid stomach ache. Rarely causes liver damage.**

- **Valproic acid *(Depakene)* Used alone or in combination with other anti-fit drugs, for ‘minor fits’ with blank staring or ‘absences’, especially when the fits occur in groups. Start with 5 mg./kg./day and increase gradually to 30 mg./kg./day; never give more than 60 mg./kg./day. Few side effects. Rarely causes liver damage.**

- **Mephenytoin *(Mesantoin)* Used like phenytoin but much more dangerous. May stop the body making red and white blood cells. Regular blood checks needed. 4 to 1 5 mg./kg./day divided into 2 doses. (We mention it here mainly to discourage its use.)**

- **Corticosteroids *(or corticotropin)* These are sometimes tried for ‘baby spasms’ and ‘jolt fits’ that are not controlled by other medicines. But long-term use of these medicines always causes serious and possibly dangerous side effects. They should be used only with highly skilled medical advice when all other possible medicines have failed.**

- **Diazepam *(Valium)* Sometimes used for ‘newborn fits’ or ‘baby spasms’, but other medicines should be tried first. May cause sleepiness or dizziness. Mildly habit forming. Give about 0.2 mg. for each kilogram of body weight per day, in divided doses.**

CAUTION DURING PREGNANCY: Many of the anti-fit drugs, especially phenytoin, **may increase the risk of birth defects when taken by pregnant women.** Also, some of the drug goes into breast milk. Therefore, pregnant women should use these drugs only when fits are common or severe without them. Women taking fit medicine should not breast feed if they are able to feed their babies well without breast milk. Phenobarbital is probably the safest anti-fit medicine during pregnancy.

TREATMENT FOR A LONG-LASTING FIT

When a fit has lasted more than 15 minutes:

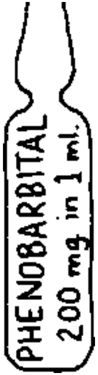
- **if someone knows how, inject IV diazepam *(Valium)* or phenobarbital into the vein.**

Doses for injectable diazepam:

Doses for injectable phenobarbital:

Figure

Adults .. 5 to 10 mg.
Children 7-12 years... 3 to 5 mg.
Children under 7... 1 mg. for every 5 kg. of body weight.



Figure

Adults........ 200 mg.
Children 7-12 years.... 150 mg.
Children 2-6 years.... 100 mg.
Children under 2 years... 50 mg.

- **or put a 'suppository' of diazepam, paraldehyde, or phenobarbital up the rectum (asshole).**

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.

Figure

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

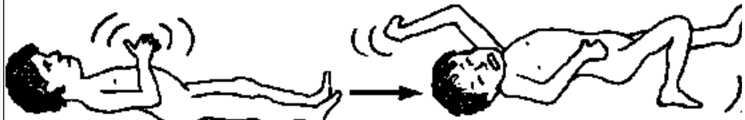
***Note:* This information is for rehabilitation workers and parents because many doctors and health workers do not treat fits correctly. With care, perhaps you can do better. However, correct diagnosis and treatment can be very difficult. If possible, get advice from a well-informed medical worker. Ask her help in using this chart. 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.**

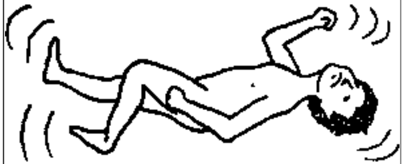
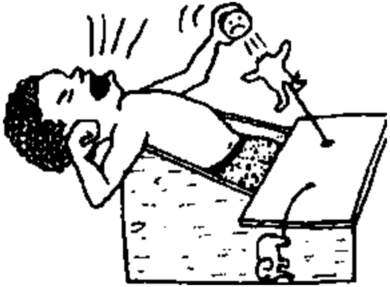
TYPE	AGE FITS BEGIN	APPEARANCE
Newborn fits  **Figure**	birth to 2 weeks	Often not typical of later fits. May show sudden limpne or stiffness; brief periods of not breathing and turning blue; strange cry; or eyes roll back; blinking or eye-jerking; sucking or chewing movements; jerks or strar movement of part or all of body. ***WARNING:*** Make sure spasms are not from tetanus o meningitis.

		With cerebral palsy in the newborn, the baby is usuall limp. Stiffness and/or uncontrolled movements usually appear months later, but the baby does not lose consciousness.
Baby spasms (West's syndrome)	3-18 months (sometimes up to 4 years)  **Figure**	 **Figure** Sudden opening of arms and legs and then bending th - or repeat patterns of a strange movement. Spasms o repeated **in groups** when waking or falling to sleep, o when very tired, sick, or upset. Most children with these spasms are retarded.
Fever fits (fits that only occur when child has a fever) 	6 months to 4 years	Usually 'big' fits (see next page) that happen only whe child has a fever from another cause (sore throat, ear infection, bad cold). May last up to 1 5 minutes or long Often a history of fever fits in the family.

Figure		***WARNING:*** Look for signs of meningitis.
Jolt or ‘lightening bolt’ fits (Lennox-Gastaut syndrome)  **Figure**	any age but usually 4-7 years	Sudden violent spasms of some muscles, without warn may throw child to one side, forward, or backward. Usually no loss of consciousness, or only brief. Many children also have ‘big’ or generalized fits. May be a history of ‘baby spasms’ (see above) in earlie childhood.

Blank spells or ‘absences’ (petit mal). (This type of fit alone is rare.)	3-15 years  **Figure**	Child suddenly stops what she is doing and briefly has strange, empty or ‘blank’ look. She usually does not fa 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 rapidl blink. These fits can be brought on by breathing rapidl and deeply. (Use this as a test.) Often confused with ‘psychomotor’ fits, which are much more common.
‘Marching’ fits (Focal fits)	any age	Movement begins in one part of the body. May spread

		certain pattern (Jacksonian march) and become generalized.  **Figure** ***Note:*** If fits that occur in one part of the body get wor and worse, or other signs of brain damage begin to appear, the cause might be a brain tumor.
Mind-and-body fits (psycho-motor fits)  **Figure**	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, odd movements such as picking at clothes. Unlike 'blar spells', these fits usually do not occur in groups but alc and they last longer. Most children with psychomotor f later develop 'big' fits.

Generalized or ‘big’ fits (grand mal)  **Figure**	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, o loss of urine and bowel control. Followed by confusion sleep. Often mixed with other types of fits. Often famil history of fits.
Temper tantrum fits (not really epilepsy) 	under 7 years	Some children in ‘fits of anger’ stop breathing and tur blue. Lack of air may cause loss of consciousness briefl and even convulsions (body spasms, eyes rolling back) These brief fits, in which the child turns blue ***before*** losing consciousness, are not dangerous.

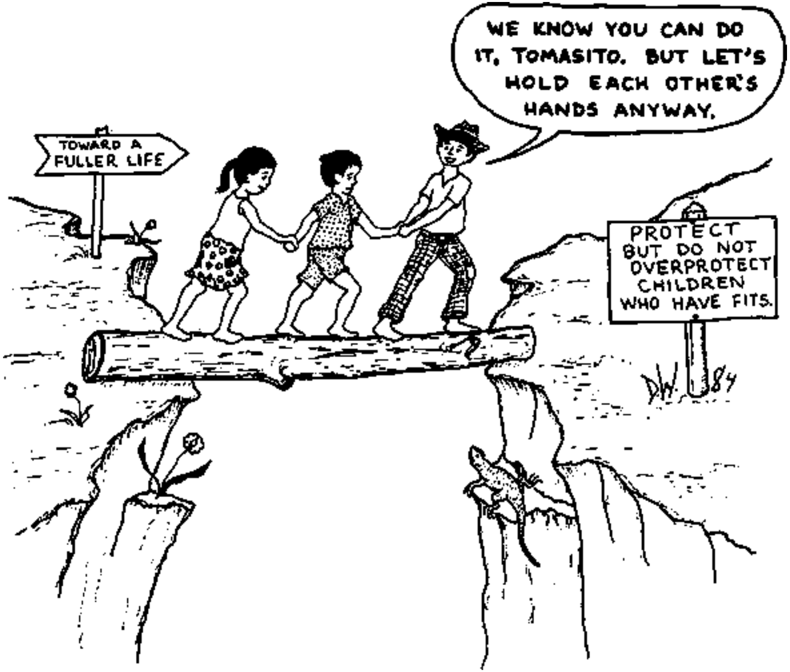
HELPING THE COMMUNITY UNDERSTAND EPILEPSY

Fits can be frightening to those who see someone having them. For this reason, epileptic children (and adults) sometimes have a hard time gaining acceptance in the community.

Rehabilitation workers need to help everyone in the community realize that epilepsy is not the result of witchcraft or the work of evil spirits. It is not a sign of madness, is not the result of bad actions by the child or parents or ancestors, is not an infectious disease, and cannot be 'caught' or spread to other people.

It is important that epileptic children go to school and take part in day-to-day work, play, and adventures in family and village life. This is true even if fits are not completely under control. 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.)

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. Village children can learn to help in the safety of such a child - especially at times when danger is greatest.



Figure

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.

2. Avoid marriage between close relatives, especially in families with a history of epilepsy.

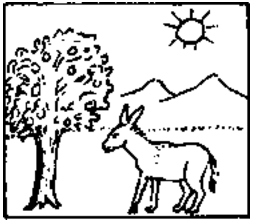
3. When children with epilepsy take their medicine regularly to prevent fits, sometimes the fits do not come back after the medicine is stopped. To make it more likely that fits will not come back, be sure that the child takes her anti-fit medicine for at least a year after her last fit. (Often, however, 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

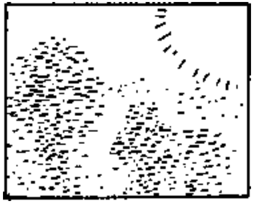
Difficulty with seeing can be mild, moderate, or severe. When a person sees very little or nothing, we say he is blind. Some children are completely blind; they cannot see anything. However, most blind children can see a little. Some can only see the difference between light and dark or day and night, but cannot see any shapes of things. Others can see shapes of large objects, but none of the details.

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.)

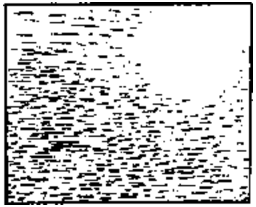
Some children are born blind. Others become blind during early childhood, or later.



what a child with normal sight can see



what a partly blind child may see (large forms but no details)



what a child sees who can only tell the direction a bright light is coming from

what a completely blind child sees

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.

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.**

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.

Methods for testing if a baby sees and for measuring the vision of children are discussed with CHILD-to-child activities.

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 very 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. In parts of Latin America, villagers believe that a bat's urine fell in the baby's eyes, or that a 'black witch moth' flew by the baby's face. These things do not really cause blindness, and as people get new information, many are leaving these older beliefs behind.

We now know that 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 ARE:

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. It results when a child does not get enough vitamin A, which occurs naturally in many fruits and vegetables (and also in milk, meats, and eggs). 'Dry eyes' develops in children who are not regularly fed any of these foods. It often appears or quickly gets worse when these children get diarrhea or have measles, whooping cough, or tuberculosis. It is much more common in children who are not breast-fed.

Dry eyes can be prevented by feeding children foods with vitamin A. Encourage families to grow and eat things like papaya, squash, carrots, and leafy green vegetables in a family garden. Be sure the child eats these foods regularly, beginning at 4 to 6 months old.

Vitamin A capsules can also prevent dry eyes, but should not take the place of a well-balanced diet. Give 200,000 units (60 mg. retinol) once every 6 months (or 100,000 units

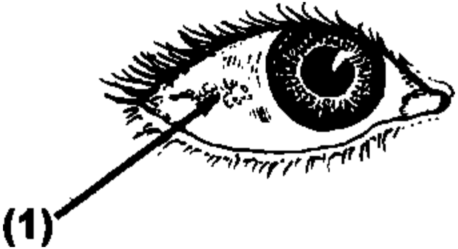
to babies less than 1 year old). Do not give this large dose more often than 6 months, because too much vitamin A can poison the child. For treatment, give 200,000 units (I.U.) of vitamin A at once, 200,000 I.U. the next day, and 200,000 I.U. 2 weeks later. Give half the dose to children under age 1. See a health worker.

SIGNS OF XEROPHTHALMIA

First sign may be night blindness. Child sees worse than others in the dark.

Figure

Next the eyes look ‘dry’. The white part loses its shine, begins to wrinkle, and forms patches of little gray bubbles (Bitot’s spots). (1)



Figure

Later, the dark part (cornea) also gets dry and dull, with little pits. (2)

Figure

Finally, the cornea may get soft, bulge, or burst, causing blindness. (3)

Figure

FOODS THAT HELP PREVENT IT

- breast milk
- dark green, leafy vegetables
- yellow, red, or orange vegetables
- whole milk
- egg yolks
- liver and kidneys

- fish

Figure

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.

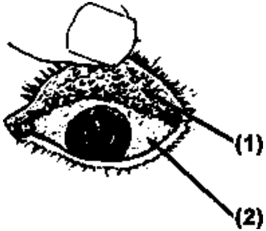
Trachoma can often be prevented by keeping the child's eyes clean and keeping flies away. To prevent blindness from trachoma, treat early with tetracycline eye ointment (see a health worker, or *Where There Is No Doctor*).

Figure

SIGNS OF TRACHOMA

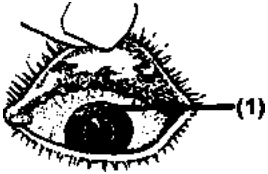
- begins like 'red eye' with red, watery, sore eyes. Or in children it may develop for months with few or no early signs.

- After a month or more small lumps form inside the upper eyelids. (1)
- White of the eye becomes inflamed or swollen. (2)



Figure

- Top edge of the cornea may look cloudy. (1)



Figure

- After years the lumps inside eyelids begin to go away, leaving whitish scars.

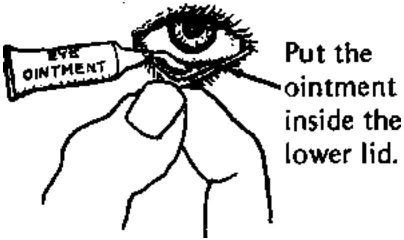
Figure

- 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*).

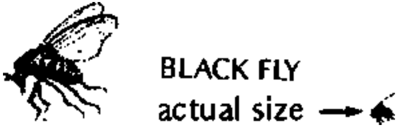
Figure

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.



Figure

5. River blindness (onchocerciasis) is a very common cause of blindness in parts of Africa and Latin America. (See *Where There Is No Doctor*.) It is spread by a kind of black fly that breeds in rivers and streams. There is no cure.



Figure

6. 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.

7. 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.

8. Eye injuries often cause blindness in children. Pointed tools, fireworks, acid, lye, and homemade bombs to dynamite fish are common causes.

WARNING

Running with a pointed object is DANGEROUS TO THE EYES.

9. Also, blindness in children is sometimes caused by other problems such as hydrocephalus, arthritis, leprosy, brain tumors, or certain medicines. Cataracts (clouding of the lens inside the eye) gradually develop in about half of older children with Down Syndrome.

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 **corticosteroid 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!*

> ***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.

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

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 craftsperson. 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. 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*	**RANI**
* Story adapted from ***How To Raise a Blind Child.*** Shanti is a little blind girl, who was born in a small village in India. When they	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

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

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 everything. 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 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. 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

usually won.

When she was 6, Rani started school. The neighbor children came for her every day. When the villagers saw them all walking down the road together, it was hard to guess which one was blind.

Figure

it.

Figure

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.

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

Have him

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.

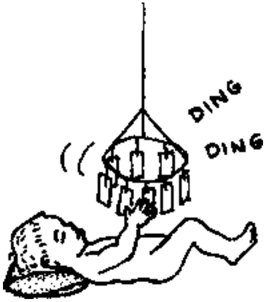
Figure

compare by touch and sound his own and other people's faces so that he begins to recognize different people.

Figure

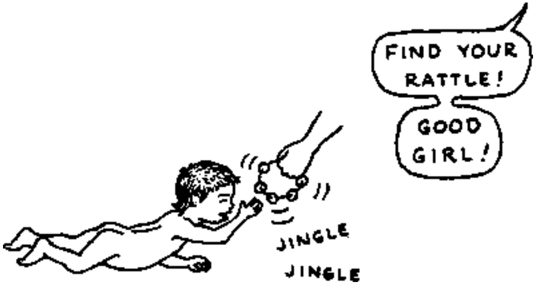
Activities to help a child develop early skills more quickly are discussed in Chapter 35. Most of these activities can help a blind child. But because he cannot see, he will need more stimulation in other areas, especially sound and touch, and in beginning to reach toward things and move about. Use toys and playthings that have many different shapes, feel different to touch, and make different sounds.

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.



Figure

At each stage of the child's development, attract her attention with a noisy plaything. Have her reach for it and then try to move toward it.



Figure

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.

Sing to the child and encourage him to move to music.

Also encourage blind children to make their own music.

Figure

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.

Figure

Figure

For ideas on homemade musical instruments.

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. 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.

However, if a blind child has the stimulation and help she needs from an early age, she will develop many skills as quickly, or nearly 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 35 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.

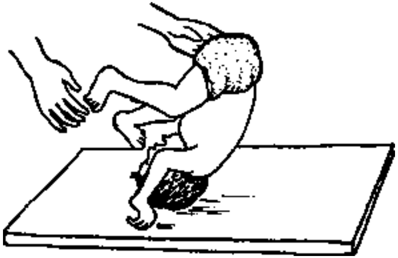
Figure

But when the child begins to walk, try to keep everything in its place, so that she does not bump into things unexpectedly and can gain more confidence moving about. If you change the position of something, show her where it is.

Figure

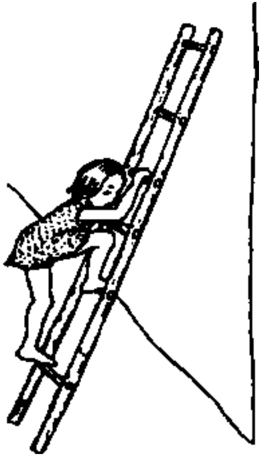
Play games and do exercises that will help the child gain confidence in moving and using his body

Figure



Figure

Encourage the child to make 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.

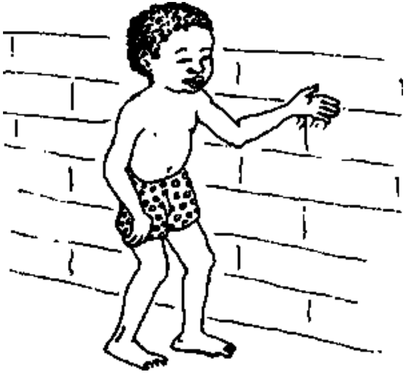


Figure

The child can learn to feel the edge of the path with her feet, ana to feel plants or other objects with her hands.

Figure

Help the child find his way by following walls and fences.



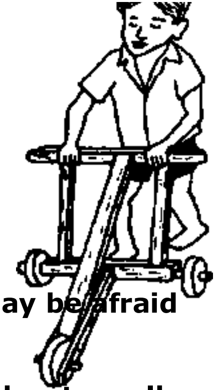
Figure

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

Figure

ready. One day he will start walking alone, first a few steps only, but finally with confidence.



Figure

Helping the blind child find her way without holding on

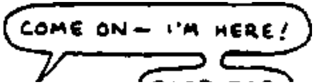
Outside the home, often a blind child will let you lead her by the hand, but may be afraid to take steps or try to find her way alone.

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) along the way.

A good way to guide a child by the hand is to let her hold one finger and walk a step behind you.

Now walk over the same path, but this time walk backward in front of her, and talk to her while you are walking.

When she feels comfortable with your walking in front of her, start walking behind her. Have her tell you the landmarks.



Figure

Figure

Figure

Little by little make yourself less and less needed. Speak less and let her go farther away from you.

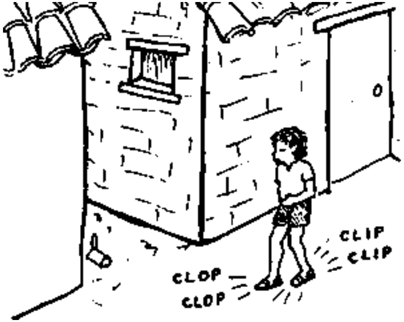
Finally let her go the whole way alone. Start by having her walk short distances. Then gradually go farther, with more turns and other things to remember.

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.

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.

Figure



Figure

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.

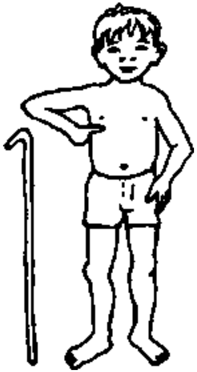
Figure

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.

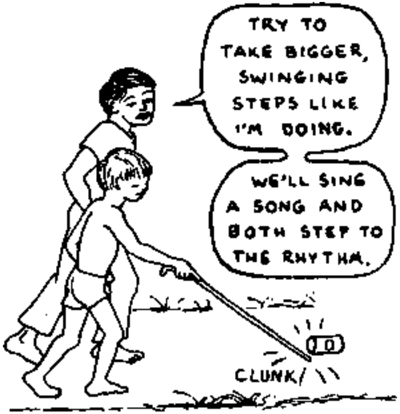
The stick should be thin and light, and tall enough so that it reaches half way between the child’s waist and shoulders. The top of the cane can be curved or straight.



Figure

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.



Figure

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

Figure

On a narrow path or rough ground, someone can lead the child by the stick.

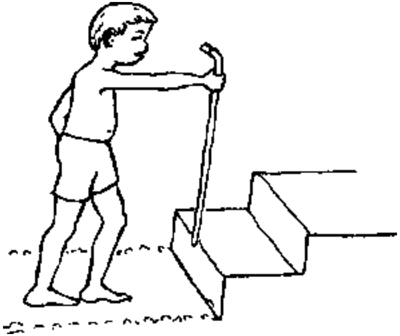
Or the child can hold the person’s elbow or wrist.

Figure

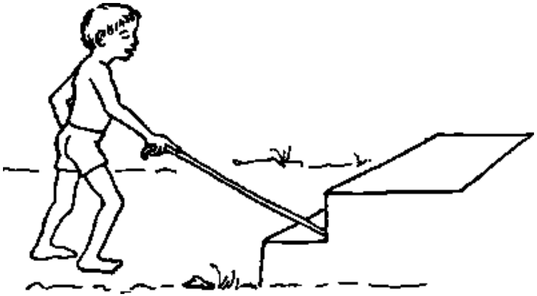
forward.

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.



CORRECT

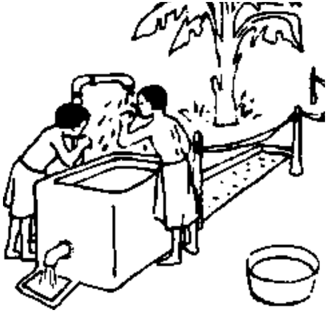


WRONG

Do not hold it like this. can cause the cane to st suddenly and hit the chi the stomach.

Figure

Putting posts or other marking where roads or paths cross can help the child find his way or know where to turn. (1)



Figure

Teach the child to listen carefully before he crosses a path or road where cars or other traffic pass.

But whenever possible, **teach him to find his way using 'landmarks' that are already there.**

Sometimes putting a gu rope or rail can help the child find his way.

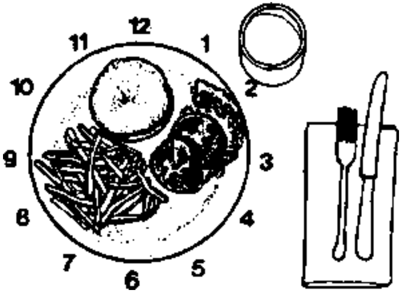
Helping the blind child to use his hands and to learn skills

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 36 to 39.

At first you may need to help the child feel things by guiding his hands.

Figure

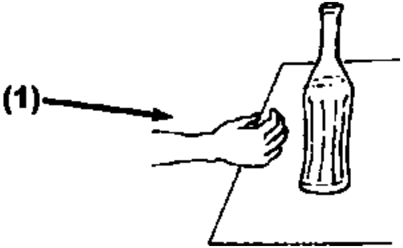
Figure



Figure

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.) (1)



Figure

Figure

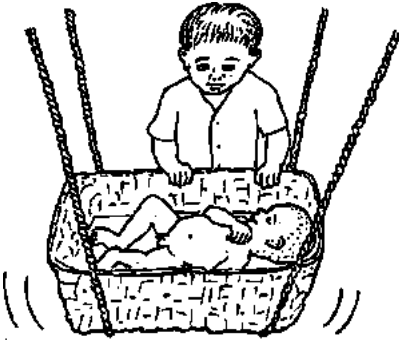
Help the child learn to recognize different shapes, sizes, and the ‘feel of things’ with her fingers. Let her play with toys and puzzles so that she learns to put different pieces together in a certain pattern or order. Ideas for toys and puzzles are.

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.

Figure

***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 enough 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.



Figure

Rani's mother teaches her how to cook by guiding her hand and explaining each step.

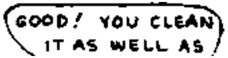
Abdul helps rock his baby brother.

Figure

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.

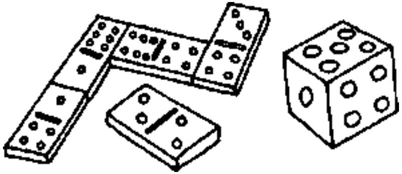
If someone takes the time to teach him, a child can begin to help in a lot of things around the home, and also in village crafts. Weaving of mats, rugs, clothing, and baskets are things many blind children can learn to do well, and it helps them learn to use their hands skillfully.



Figure

Figure

Also, look for games and toys that help the child develop her ability to feel fine details and small shapes with her fingers.



Figure

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 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.

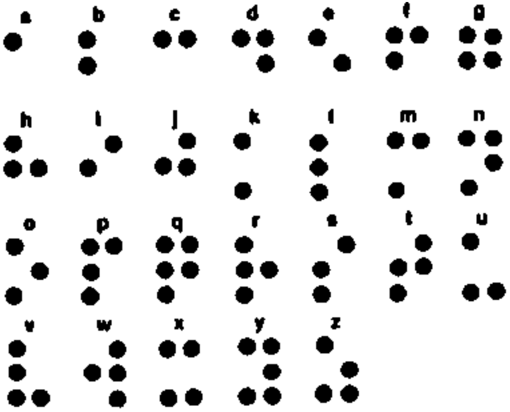
In most countries there are special schools that teach blind children to read and write 'braille'. Braille is a system of raised dots that represent letters and can be read with the fingertips. It was invented many years ago by a blind boy from France named Louis Braille.

Most village children do not learn braille in school. However, there are many other ways that they can 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 schoolchildren 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.

Figure

THE BRAILLE ALPHABET



Figure

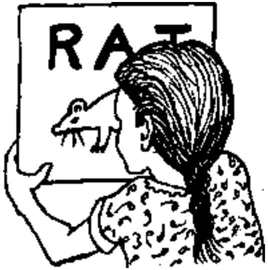
Louis Braille invented this dot alphabet at age 14. The dots are pressed into a thick paper from the opposite side with a pointed tool called a ‘stylus’.

IMPORTANT: In order to keep up with her studies a blind child will need help. In school another

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.

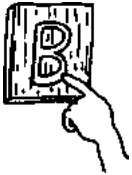
If she can see at all, to help her learn the letters, make them very **BIG**. Use white paper and dark ink.



Figure

To help the child learn the shape of letters by feel, you could make them i these ways.

Figure



Figure

Figure

rope glued or pinned to wood or cardboard

grooves cut into wood

letter cut out of cardboard and glued to thick paper

Figure

In the schoolroom, a **pan with soft clay or mud** is helpful for learning to write and feel letters.

Figure

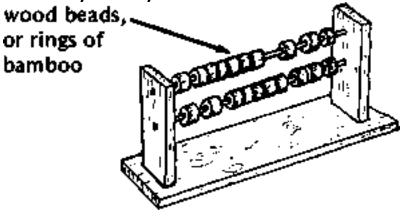
Children can practice writing outside in **sand, mud,** or **clay**.

board with string stretch holes

When the child begins to writ stretch string lines across the help her write in straight line extra dark lines.

To help the child begin to count you can make a simple **'counting frame'.** The child

When the child becomes more skilled with numbers, she can learn to use counting frame called an **'abacus'** which has beads on wires. The beads s down to form numbers. With practice, a blind child can learn to add and s can slide the beads or rings from one side to the other to count, add, and subtract.



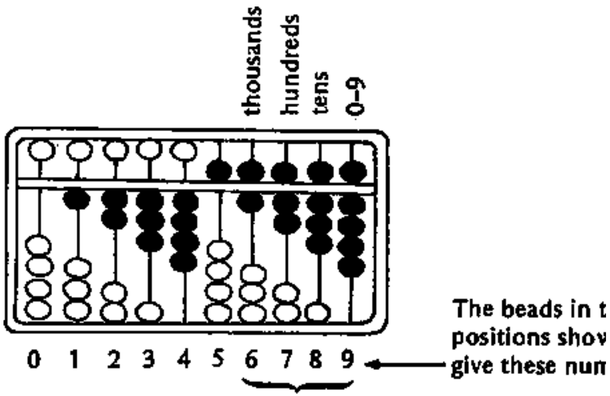
Figure

abacus as fast or faster than other children can do it on paper.

A pegboard like this can help a child learn numbers through touch - and help him learn to feel small differences in things.

Figure

AN ABACUS



These 4 wires now read 6789.
Notice that each bead above the center bar equals 5 times each bead directly below it.

Figure

Work

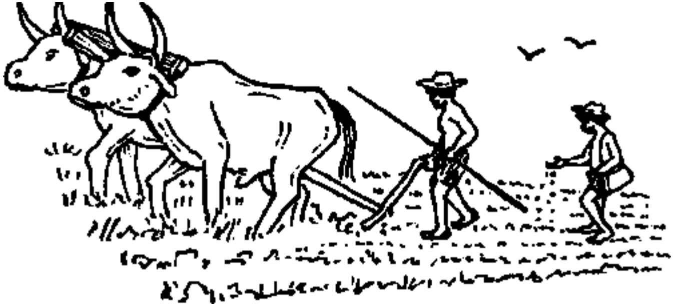
As a blind child grows up, he or she can learn to do many different kinds of work. On page 509 in Chapter 54 we list many of the different kinds of work that disabled persons can do. Those types of work marked with a * have often been done by blind persons.

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.

Figure

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.



Figure

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.**

- ***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, every day.

- **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) 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. (For example, the juice of 'hiza', a poisonous fig tree in Mexico, can burn the eyes like lye.) Get good early treatment for any eye injury.**

- **Warn children about throwing rocks and sticks, or shooting slingshots 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).

Figure

- **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.**

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.

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 sounds 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 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.)

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 a child with a hearing loss, the biggest problem is learning to communicate. Because she 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 became 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 deaf only. (See "Causes of Deafness.")**

4. **how soon the problem is recognized.**

5. how well the child is accepted, and how early he is helped to learn other ways to communicate.

6. the system of communication that is taught to the child ('oral' or 'total').

CAUSES OF DEAFNESS

Deafness is ***not*** caused because the child did something wrong or because someone is being punished.

Common causes before a baby is born:

- **hereditary** (occurs in certain families, although the parents themselves may not be deaf). Usually a child has no other disability, and learns quickly.
- **German measles** during early pregnancy. Often child also has brain damage and learning problems.
- **Rh factor**. Child often has other disabilities also.
- **Prematurity** (born early and small). Two out of 3 have other disabilities also.
- **lack of iodine** in mother's diet (common in areas where many people have goiters). May show signs of mental retardation or cretinism.
- certain **medicines** taken by the mother while pregnant, such as corticosteroids and phenytoin.
- difficult birth, baby slow to breathe.
- dwarfism and brittle bone disease.

Common causes after birth:

- **ear infections** - especially long-lasting repeated ***infections*** with pus.

Figure

- **meningitis** (often child has other disabilities and ***behavioral*** problems).
- **certain medicines** (streptomycin, and related antibiotics).
- **frequent very loud noise.**

Other causes. There are many other less common causes of deafness. In 1 out of 3 children the cause is not known.

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 recognized 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. Does the baby show surprise or blink when you make a sudden loud noise? As the baby grows, does he turn his head or smile when he hears familiar voices? Has he begun to say a few words by 18 months of age? Does he say a lot of words fairly clearly by age 3 or 4? If not, he may have a hearing problem. As soon as you suspect a problem, test the child’s hearing.

Simple tests for hearing. If it seems the child does not hear well, when possible, take him

to a specialist for testing.

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.

TONIO	SANDRA
Although Tonio 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, Tonio seemed to be doing fairly well. He began to walk and play with things. Then his sister, Lota, was born. Lota smiled and laughed more than Tonio when their mother talked or sang to her. So their mother talked and sang to Lota more. By the time Lota was 1, she was already beginning to say a few words. Tonio had not yet begun to speak. “Are you sure he can hear?” a neighbor asked one day. “Oh yes,”	When Sandra was 10 months old, her 7-year-old brother, Lino, learned about testing for deafness as part of the CHILD-to-child program at school. 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 Sandra did not hear well. They took Sandra to a small rehabilitation center. A worker there tested Sandra and agreed she had a severe hearing loss. The village worker explained what the family could do to help Sandra 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 Sandra won’t understand. But she’ll watch and learn. In time she’ll begin to

said his mother. She called his name loudly, and Tonio turned his head.

When he was 3, Tonio could only say 2 or 3 words. Lota, at age 2, now spoke more than 200 words. She asked for things, sang simple songs, and played happily with other children. Tonio was more moody. Mostly he played by himself. When he played with other children it often ended in fighting-or crying.

Lota behaved better than Tonio. Usually, when her mother told her not to do something and why, she understood and obeyed. Often, to make Tonio obey, his mother would slap him.

One time in the village market Lota asked for a banana and her mother bought her one. A moment later, Tonio quietly picked up a mango and began to eat it. His mother slapped him. Tonio threw himself on the ground and began to kick and scream.

use signs herself”

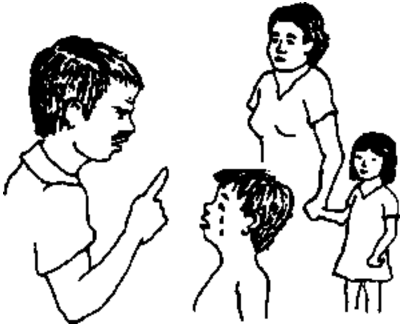
“If she gets used to signs, won’t that keep her from learning to speak?” asked her father.

“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.”

Sandra’s family began using signs as they spoke to each other. Months passed, and still Sandra did not begin to speak or to make signs. But now she was watching more closely.

By age 3, Sandra 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 ‘Lino’. By age 5 she had only learned to ‘lip read’ a few words. But with signs she could say over 1 000 words and many simple sentences.

When Tonio’s father heard what had happened in the market, he looked angrily at Tonio 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?”



Figure

Tonio 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.

Tonio’s behavior got worse and worse. At age 4 his mother took him to a health worker, who tested Tonio and found that he was deaf.

Figure

Sandra was happy and active. She liked to color pictures and play guessing games. Lino began to teach her how to draw letters. One day she asked Lino when she could go to school.

Now Tonio’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. Tonio seems a little happier and speaks a few more words. But he still has a lot of trouble saying what he wants.	

WHERE CAN YOU GO FOR HELP?

A child who does not hear well needs extra help. Where you can look for help depends on where you live and on what resources are in your community and in your country. Here are some possibilities:

- **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.**

- **The National Association of the Deaf (or other group run by the deaf). Most countries have associations of deaf persons. These can give you information about the national sign language in your country, and perhaps send books for learning it. They can tell you about training programs for the deaf (government, private, and religious) 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.

- **‘Special education’ programs or schools for the deaf. Many countries have schools 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. Bad programs try to make all deaf children communicate only by lip reading or speech. For many children this can lead to failure, anger, and emotional harm. Try to get advice from educated deaf persons.**

At first it may be difficult for parents to let their child go away to school. But learning to communicate well can be important to the child’s life. Be sure to check the costs and plan ahead. Some schools may be free or have low fees.

Deciding what to do for a deaf child

Not all children with hearing loss are 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.

- **If a child is only partly deaf, sometimes we can help her to hear more clearly, to understand more speech, and perhaps learn to speak.**

- **A child who has no hearing at all usually cannot be helped to hear. But if he became deaf after he began to speak, perhaps he can be helped to ‘read’ people’s lips and to improve his speech.**

- **If the child was born deaf and has never heard speech, learning to lip read and speak is always very slow and difficult, and is usually not very successful. It is**

better to help the child learn to communicate in whatever ways work best for her: first with her face, body, arms and hands, then possibly adding pictures, reading and writing, finger spelling, and as much lip reading and speech as she is able to learn.

- **If the child comes from an area where there are many deaf people who communicate with each other in a national sign language, it is probably best to have people in the deaf community help teach the child and her family their language. That way, she can learn to communicate with deaf people as fully and well as hearing people communicate with each other.**

- **But if the child lives in a small village where there are few deaf people, none of whom know the national sign language, learning that language may not help the child much. Probably it makes more sense for her to learn ways to communicate as best she can with those who can hear. Again, this probably means a combination of methods, based on the signs and gestures people already use in the village. With these, the child can also use pictures, and later perhaps, reading and writing.**

- **Remember, most children with hearing loss can learn quickly. But some may have brain damage or disabilities that affect their ability to learn or to control their hands, lips, or voices. You will need to figure out ways to help these children communicate in whatever way they can: with sets of pictures, head movements, or eye movements.**

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.

Helping a child to hear better

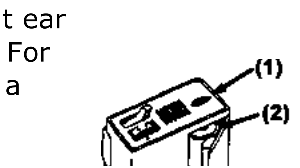
Children who are not completely deaf can sometimes be helped to hear better:

- **When possible, 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. (*Note:* For children whose hearing loss comes from brain damage, surgery will not help.)**
- **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.**
- **Some children can hear better with aids that make sounds louder. A 'hearing aid' allows some children to understand words 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. If it appears the child will benefit a lot from a hearing aid, it helps to begin as early as age 1 or 2.**

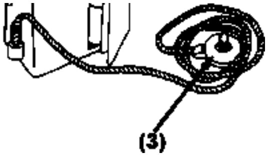
The simplest aid is a **hand cupped** behind the ear.

Better is an **'ear trumpet'.** You can make one out of a cow horn, cardboard, or tin.

Better still (for some children) is a **'hearing aid' with batteries.** But usually these are very expensive. For best results, it should be fitted by a specially-trained worker after the



child’s hearing has been carefully tested.



Figure

(1) microphone

(2) batteries

(3) Piece that fits into ear (best if molded to fit the specific child). In a growing child it will need to be changed often.

Figure

Figure

Figure

CAUTION: If you get a 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 to get more.

- **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.

Figure

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.

Figure

DIFFERENT WAYS TO HELP A CHILD COMMUNICATE

<table>
<tr><td colspan="2">COMMUNICATION BY SHOWING


Figure</td><td>HELP WITH HEARING AND SPEAKING


Figure</td></tr>
<tr><td>LIP READING</td><td>COMMUNICATION BY</td><td>FINGER SPELLING</td></tr>
</table>

Figure

PICTURES AND POINTING

Figure

Figure

READING AND WRITING

Figure

SIGN LANGUAGE

"Talking with the hands"

Figure

Oral communication

Oral communication (communication by mouth) combines helping a child use her limited hearing as much as possible, with lip reading, and with learning to speak. In many countries, schools for deaf children teach only oral communication. Unfortunately, oral communication usually only works well for children who can hear the differences between many words, or for children who became deaf after they learned to speak.

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 lip reading 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 fully as possible with her family and community. It is an approach that is friendly, flexible, and adaptable to individual and local needs.

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 or words. As a result, deaf persons often manage fairly well in the community. They can "say" and understand a lot.

We know families from villages like these who took their deaf child to ***'speech therapists'*** in the city. Often the parents and child had already begun to communicate with each other by using the local signs and inventing more of their own. The child was happy and learning, fairly well. But the therapists told the parents that they were wrong. They told them that they must not let the child use signs, because if he got used to signs he would never learn to speak. They said the child should be put in a 'special education program' and taught 'oral communication'. But since the only programs of this kind are in the cities (and often have a 3-year waiting list) the parents took their child back to the village. Trying to follow the therapist's orders, they tried not to use signs with their child, and punished him when he used them. As a result, both the parents and child felt frustrated, guilty, angry, and hurt. The child's learning and social development were held back. His chances of learning to speak became less than they were when everyone happily used the village system.

Fortunately, most of these families in time realized that they simply could not manage without using signs, and gradually went back to accepting 'total communication'.

In the richer countries more and more special educators and speech therapists are beginning to favor total communication. They have changed to this approach partly because deaf persons have organized and demanded it. **Disabled persons in poor countries, including deaf persons and their families, also need to organize. They need to help professionals listen to them, and to respond to their needs in more realistic ways.**

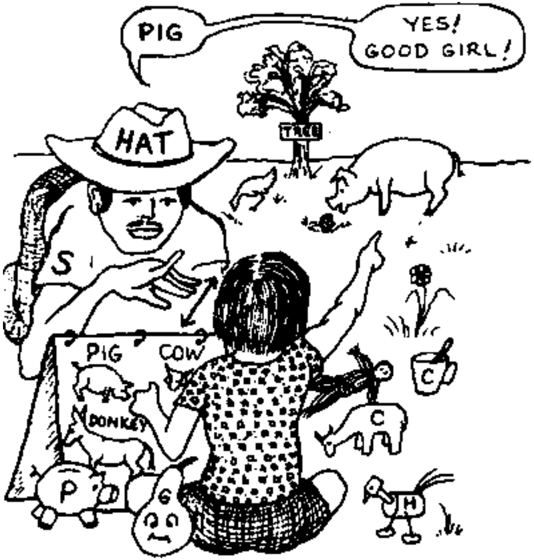
Helping a child learn 'total communication'

- **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.**



Figure

- **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 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 like 'Simon says' that help children use their eyes, ears, and bodies, and copy each other.**

- **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.**

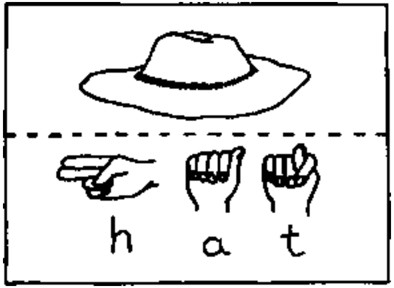
- **Make a list of the words that other children her age use, and that you most want the child to learn. Include:**

- **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
- **people:** you, I, he, she, it, we, they, Mama, Papa, Juan, Maria, and other family members
- **description words:** small, big, up, down, fat, thin, good, bad, hot, cold, day, night

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 letter or name of 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.**



Figure

SIGN LANGUAGE

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. Some children's games use hand signs. For example:

"Here's the church."

"And here's the steeple."

"Open the doors."

"And see all the people."

Figure

Figure

Figure

Figure

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!

Figure

Figure

Figure

Figure

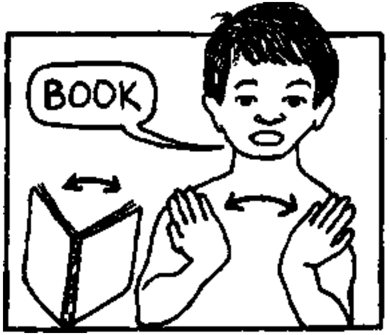
Figure

The family had begun to figure out its 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:

- **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. Examples are American Sign Language (ASL), which is used in the USA and Canada, and Mexican Sign Language.**

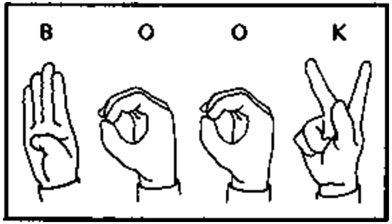


Figure

- **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**

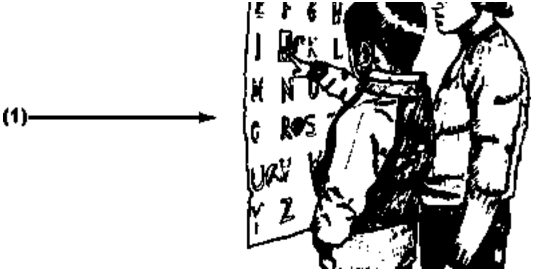
sign. This is harder for children to learn who cannot read, but can make learning to read easier and more fun. Examples are English Sign Language and Spanish Sign Language.

- **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. For English, the British use a 2-handed system and the Americans use a one-handed system. Try to learn the system that is most used in your country.**



Figure

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. (1)



Figure

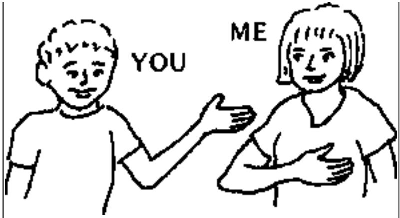
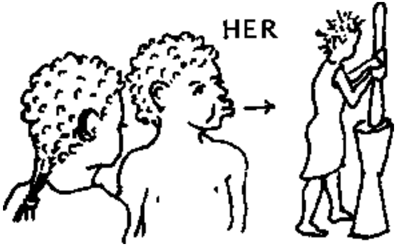
Learning to sign

If possible, contact the Association of the Deaf in your country, and see if you can get a guidebook to sign language adapted to your local area or spoken language. If this is not possible, you can use the local signs and gestures, and invent more signs of your own.

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:

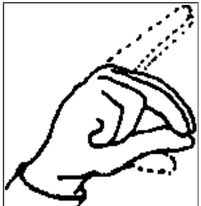
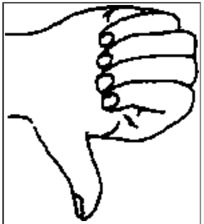
- **Choose signs that will not offend the local people. (Deaf people already have a difficult time being accepted.) Here are some examples:**

In the USA a pointing finger is used to indicate different persons (me, you, her, them).	In some countries it is not polite to point a finger, so an open hand is used.	In other places even pointing with an open hand is not polite, and people point with their lips. HFR

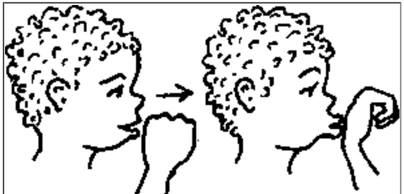
 **Figure**	 **Figure**	 **Figure**
In the signed alphabet used in the USA and Canada the letter ‘T’ is made like this.  **Figure** However, in many countries, this is an offensive gesture	Therefore, in this book we also use the ‘T’ sign from Spanish and Danish.  **Figure**	Also avoid confusion. For example, the sign for “WHERE” in the USA is a common gesture for “NO” in Mexico.  **Figure**

- **Use local signs. If people in your area already have a gesture or sign for something, use that instead of a new or foreign one. For example:**

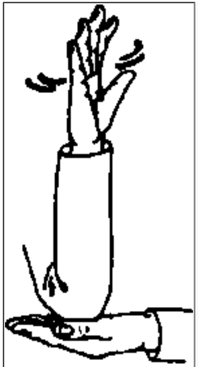
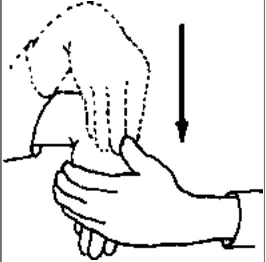
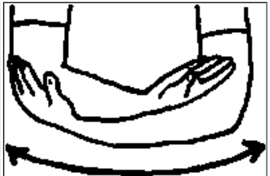
The American	Some	In Jamaica NO and NOT are	The American	In Nepal this sign is

sign for NO is this:	countries use this sign for NO:	often said by a negative look and shake or tilt of the head.	sign for SLEEP is this:	used for SLEEP. It is understood almost everywhere.
 **Figure**	 **Figure**	 **NO, NOT ME**	 **Figure**	 **Figure**

- **Use hand shape, position, movement, and direction to make different signs. The expression on the face also adds to meaning. For example, here are signs for MOTHER:**

in Brazil	in Australia	in Spain	in Thailand
 **Figure**	 **Figure**	 **Figure**	 **Figure**

- **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.**

TREE	DISH	POCKET	BABY	TURTLE
 **Figure**	 **Figure**	 **Figure**	 **Figure**	 **Figure**

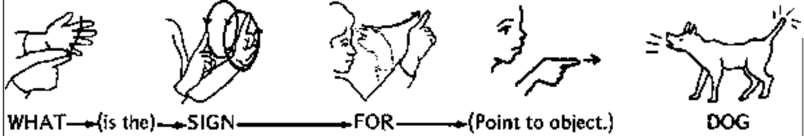
- **Figure out patterns and series of similar signs for related things and actions, and for opposites. For example:**

STAND	SIT DOWN	JUMP	PUSH	PULL
				 **Figure**

Figure

See other signs with fingers as legs.

- **Learn new signs by pointing to things.**



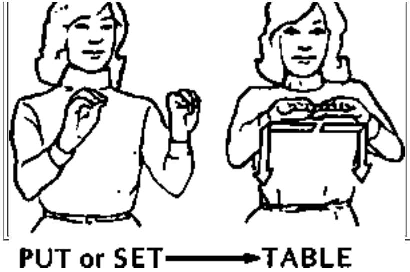
Figure

Or if you can read and write, use finger spelling.

Figure

- **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.**

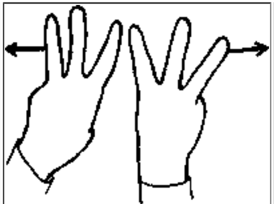
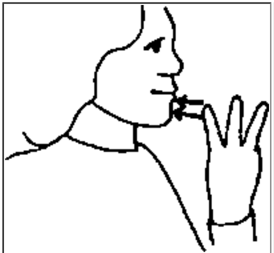
Set the table.	Will you give me a banana, please?
	



Figure

Figure

- **Decide whether or not to use letters of the alphabet to make some signs. In some sign languages the first letter of a spoken (written) word is used as the sign for that word. At first this will mean nothing to a child who cannot read, and will be harder. But it can help prepare the child for learning to read and to finger spell. Again, be systematic:**

The sign for 'W' is	WALL	WATER	WATERMELON
 **Figure**	 **Figure**	 **Figure**	 **1.**

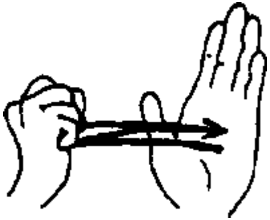
			 **2.**

(Tap with finger.)

Be sure that letter-based signs agree with the word in ***your*** language. In Spanish, "watermelon" is "sanda," so the English sign makes no sense. The Spanish sign is:

SANDA

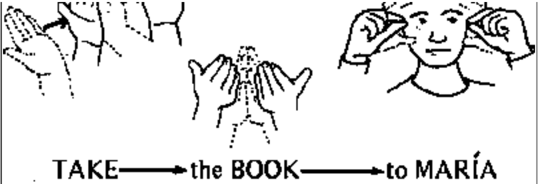
(Tap with fist.)



Figure

- **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.**

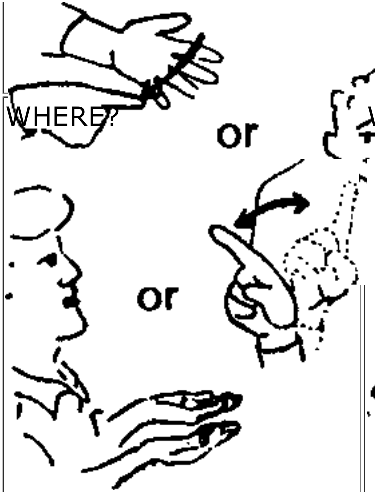
If Mara a looks like this,	you might sign her name like this:	

			 **Figure**
 **Figure**	 **1.**	 **2.**	
	Sign ‘M’ for Mara,	and then the sign for ‘glasses’.	(Move hands in direction it should be taken.)

HOW TO ASK QUESTIONS

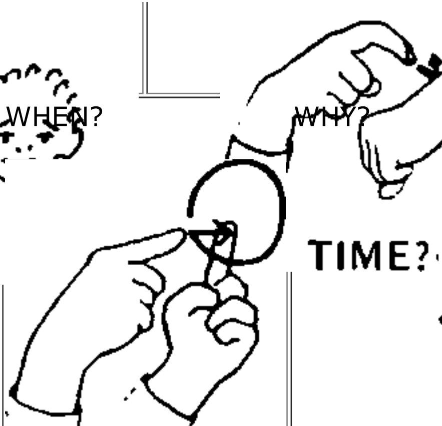
WHAT?	What time is it?	What di 

WHERE?



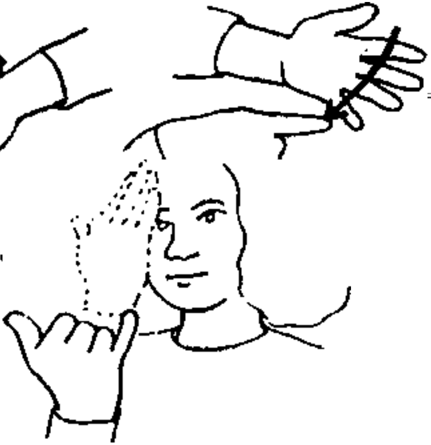
Figure

WHEN?



Figure

WHY?

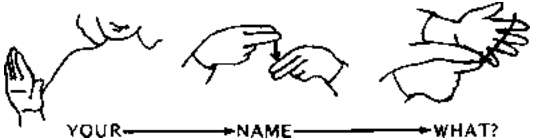


Figure

WHO?

Fi

What is your name?



Figure

IS

Note: ‘I
‘was’, a
often n
“What i

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. 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 7, and 'we' the letter 'W'). Change these signs if you speak a different language, or if you want to avoid signs based on letters.

I, ME	YOU	THEY, THEM	MALE (MAN)

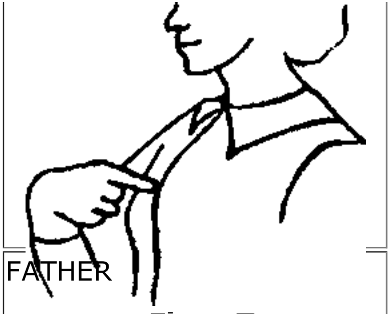
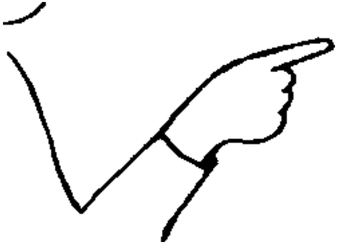
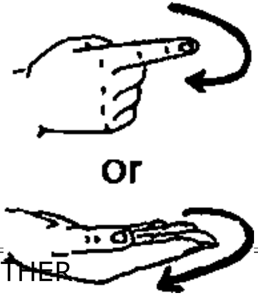
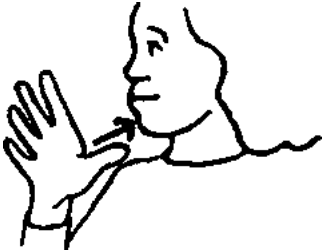
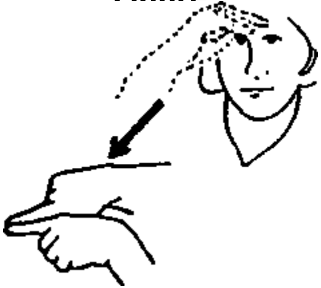
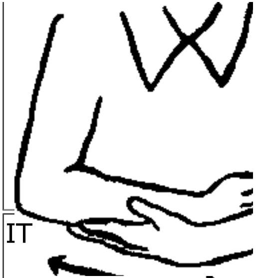
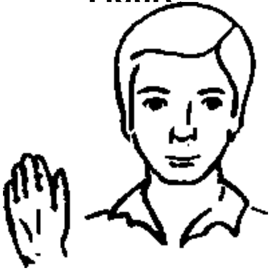
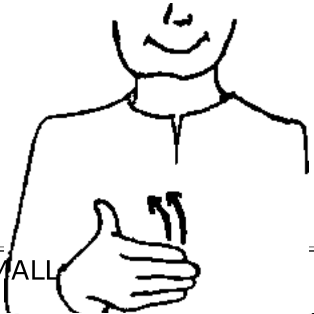
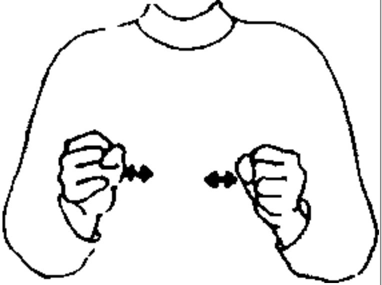
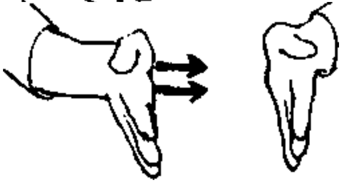
			
FATHER  **Figure**	MOTHER **Figure**  **Figure**	BROTHER **Figure**  **Figure**	SISTER **Figure**
GRANDFATHER	GRANDMOTHER	FRIEND	BABY

		 **Figure**	
HE, HIM  **Figure**	SHE, HER  **Figure**	HIS, HER, THEIR, YOUR  **Figure** Direct sign toward person.	IT  **Figure** Or point to object.
GOOD	BAD	HAPPY	SAD

Figure



HOT	COLD	SMALL	LARGE
 Figure	 Figure	 Figure	 Figure
UGLY	PRETTY	FAT	THIN

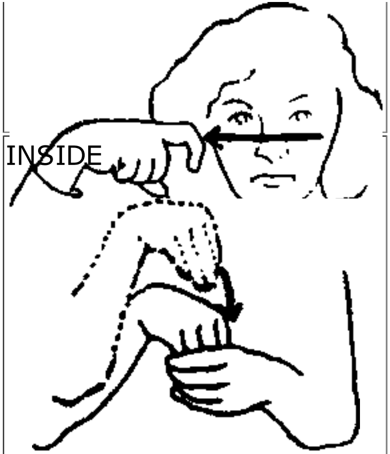
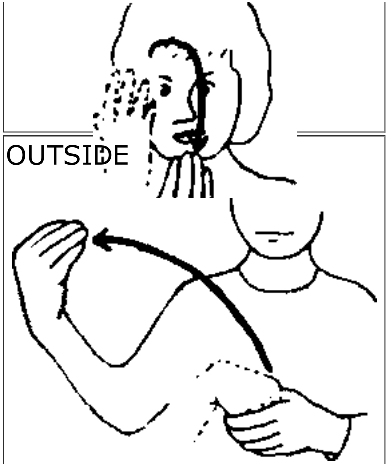
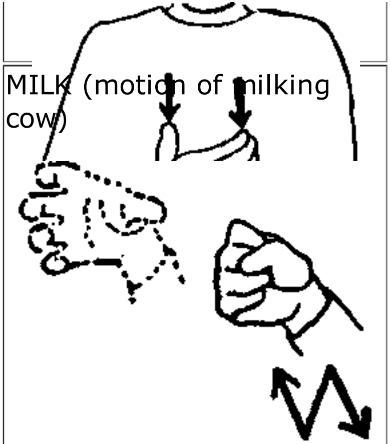
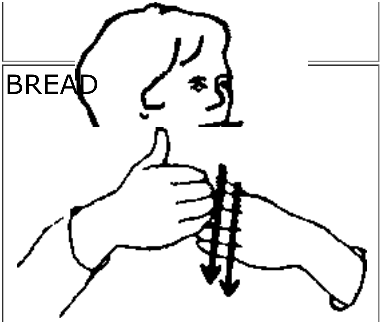
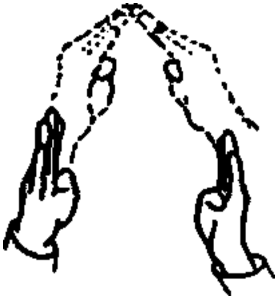
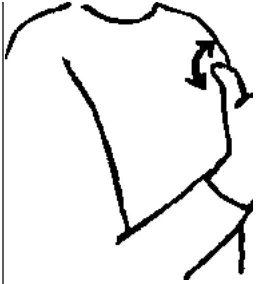
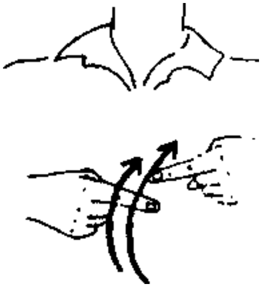
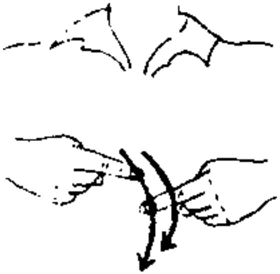
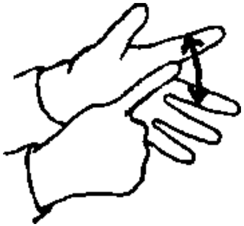
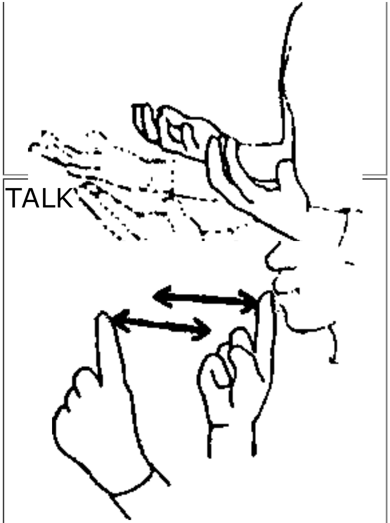
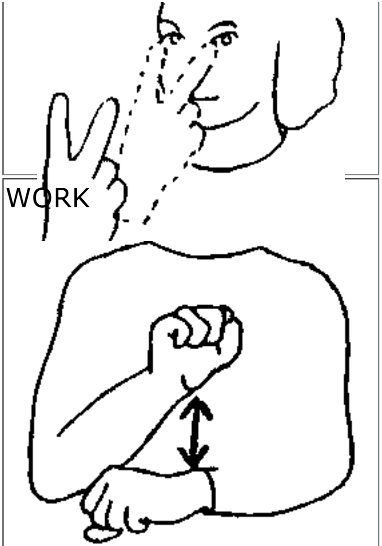
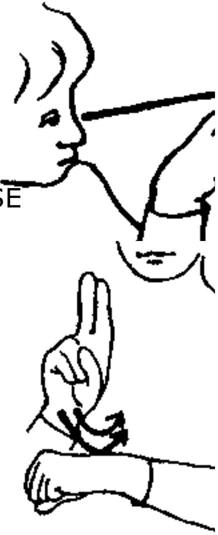
INSIDE  **Figure**	OUTSIDE  **Figure**	UNDER  **Figure**	TIRED  **Figure**
HUNGRY	EAT 	FOOD	THIRSTY 

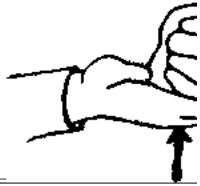
	Figure		**Figure**
MILK (motion of milking cow)  **Figure**	SOUP  **Figure**	BREAD  **Figure**	BOWL  **Figure**
HOUSE  **Figure**	VILLAGE, COMMUNITY, CITY, TOWN  **Figure**	SCHOOL  **Figure**	

			in Americ  **Figure**
BLIND  **Figure**	DEAF  **Figure**	HEARING AID  **Figure**	FORGET  **Figure**
RED	GREEN	BLUE	YELLOW

 Figure	 Figure	 Figure	 Figure
COME  Figure	GO  Figure	BEGIN  Figure	STOP  Figure
WANT	DON’T WANT	SEE	LOOK

TALK  **Figure**	MAKE  **Figure**	WORK  **Figure**	USE  **Figure**
TAKE (CARRY)	BRING	PUT	HELP (ASSIST)

Figure



Figure

STAND

Figure

LIE DOWN

Figure

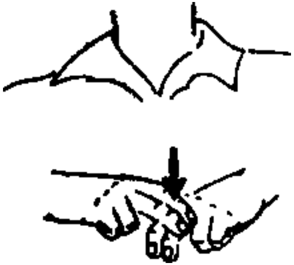
WALK

Figure

RUN

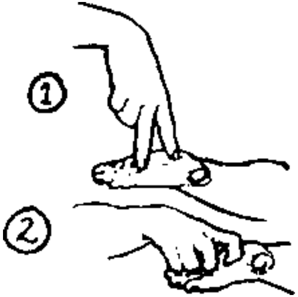
Figure

SIT

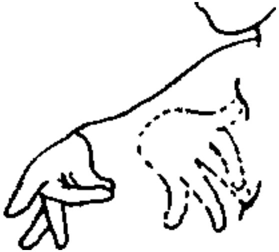


Figure

SQUAT



LIKE



Figure

LOVE

	Figure		**Figure**
CHICKEN  **Figure**	GOAT  **Figure**	HORSE  **Figure**	COW  **Figure**
DAY	MORNING  **Figure**	AFTERNOON  **Figure**	NIGHT  **Figure**

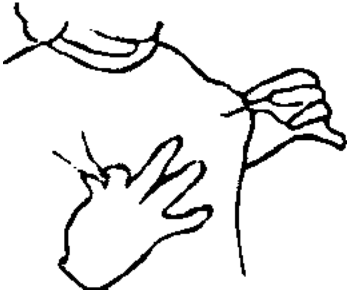
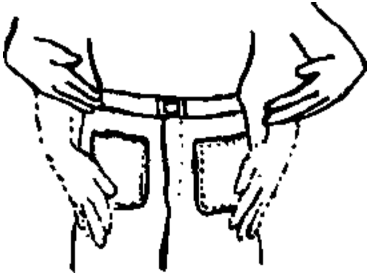
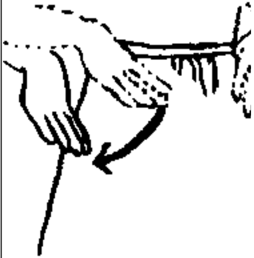
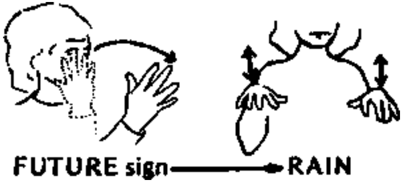
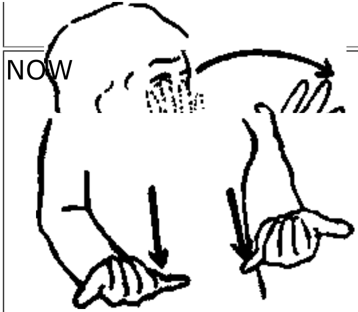
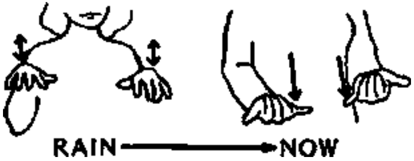
			
HAT  **Figure**	SHIRT  **Figure**	PANTS  **Figure**	SKIRT  **Figure**
FUTURE	PAST 	It is going to rain.  	

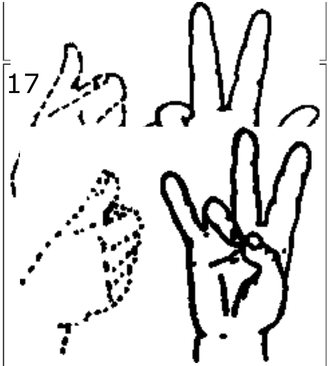
	Figure	**Figure**
NOW  **Figure**	It is raining.  **Figure**	Throw the ball to h 

NUMBERS (one of many systems)

1  **Figure**	2  **Figure**	3  **Figure**	4  **Figure**
5	6	7	8

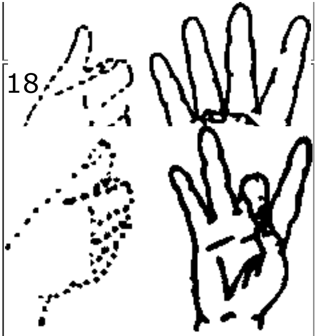
 **Figure**	 **Figure**	 **Figure**	 **Figure**
9  **Figure**	10  **Figure**	11  **Figure**	12  **Figure**
13	14	15	16

17



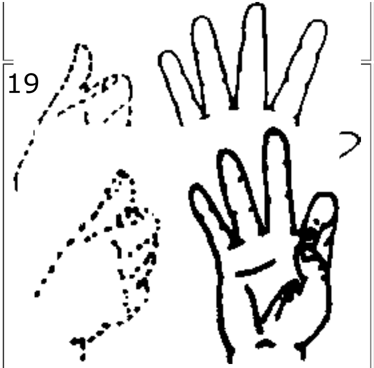
Figure

18



Figure

19



Figure

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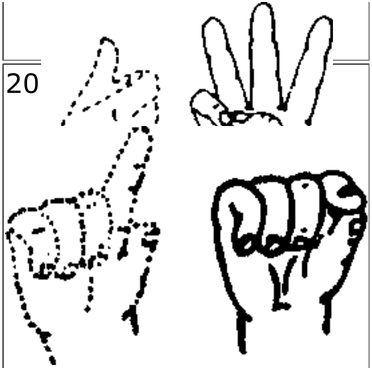
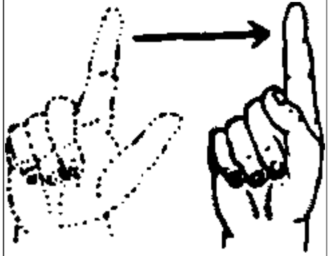


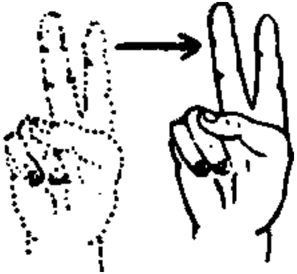
Figure

21



Figure

22

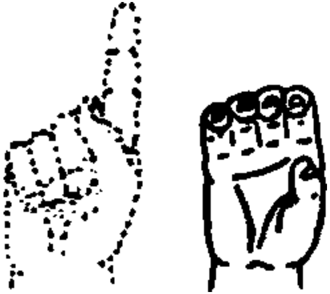


Figure

50

Figure

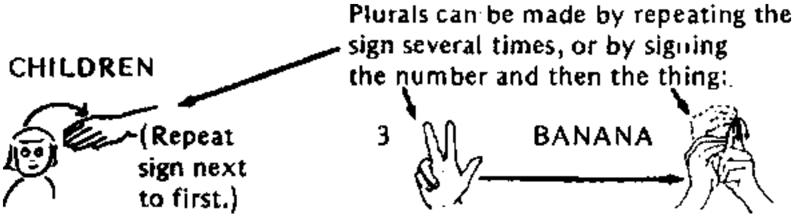
100



Figure

<table>
<tr><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="4">Plurals (more than one)

Figure



Plurals can be made by repeating the sign several times, or by signing the number and then the thing:

Figure</td></tr>
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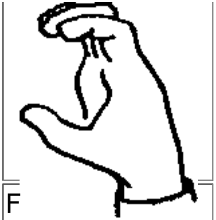
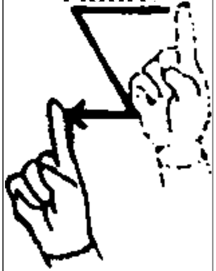
ONE-HANDED SIGN ALPHABET (American)

A	B	C

		
D **Figure**  **Figure**	E  **Figure**	F **Figure**  **Figure**
G	H	I

		
J  **Figure**	K  **Figure**	L  **Figure**
M  **Figure**	N  **Figure**	O  **Figure**
P	Q	R

 **Figure**	 **Figure**	 **Figure**
S  **Figure**	T American  **Figure**	T Danish  **Figure**
U	V	W

	 Figure	 Figure
X  Figure	Y  Figure	Z  Figure

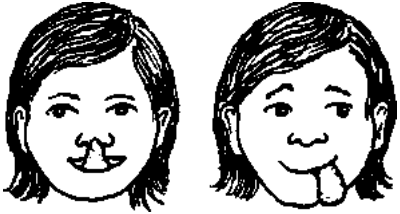
Helping the child learn to make sounds and speak

1. If the child hears at all, encourage her to notice and listen to different sounds, as discussed.

2. Play games and do exercises to help her learn to use her mouth, tongue, and lips. Have her press her lips together as if saying “mmm,”  make a circle like ‘O’ , and stretch

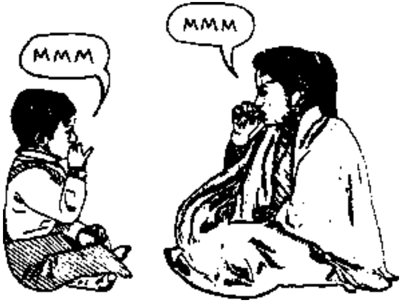
her mouth and smile as if saying "eee"  **.**

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.



Figure

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 difficult sounds like V, 'w', 'j', 's', 'n', 'r', and 'z' for later.)



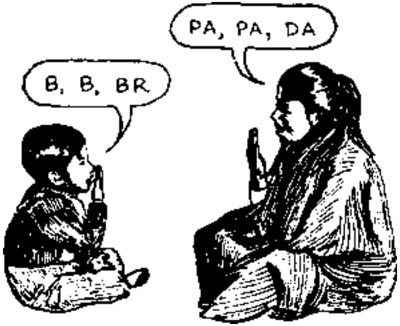
Figure

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.

Figure

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', 'he', 'ho', 'm', 'p', 'b', and 'f'.

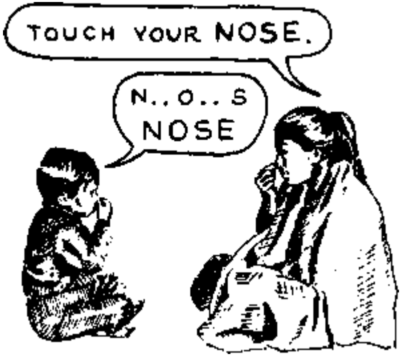
In the same way, have him feel the air move when he 'blows his nose' with his mouth closed. Using this, try to teach sounds like 'n' and 'l'.



Figure

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.



Figure

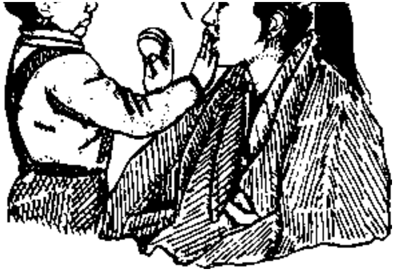
8. Little by little, help the child learn more words and practice using them through games and daily activities. Have her learn her own name and the names of family and friends. Build up a word list as explained. But do not try to go too fast. Take time to help her say a few words fairly clearly before 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. Do not start teaching lip reading until the child is at least 3 years old.

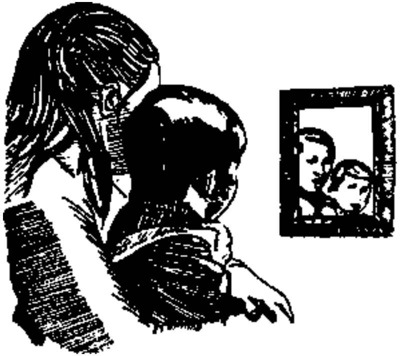
Sit in front of the child in good light, and show him something, for example, a ball. Say “ball,” moving your lips clearly and speaking slowly. Let the child see your lips move, and watch your face. Repeat the same word many times.

Then have the child try to imitate you, and feel his own lips as he does.



Figure

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.



Figure

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.

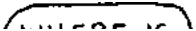
Unfortunately, some sounds and words look exactly the same on the lips - the sounds ‘k’, ‘g’, and ‘h’, look the same. ‘P’, ‘b’, and ‘m’ look almost the same. ‘T’, ‘d’, ‘s’, and ‘z’ look the same. And so do ‘ch’ and ‘j’. To help the child tell similar words apart, use hand signs or give him small ‘clues’, 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’.

Figure

Figure

Figure



Figure

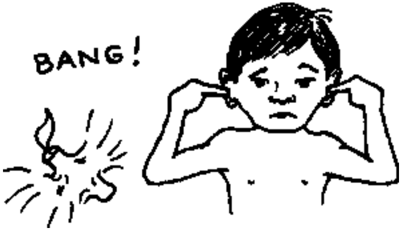
PREVENTION of deafness

- **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 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.**
- **Vaccinate the baby against measles (and, if possible, mumps),**
- **Take precautions to prevent brain damage and cerebral palsy.**
- **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.**



Figure

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 craftsworkers, 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, Cretinism, and Other Causes

Down Syndrome, Cretinism, and Other Causes

Mental retardation is a delay, or slowness, in a child’s mental development. The child learns things more slowly than other children his 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.

Mental retardation ranges from mild to severe. The child who is *mildly retarded* takes longer to learn certain skills. But with help he can grow up to care for himself and take an active, responsible part in the community. The child who is *severely retarded,* as he grows older, may stay at the mental age of a baby or young child. He will always need to be cared for in some ways.

Mental retardation cannot be cured. However, all mentally retarded children can be helped to progress more quickly. The earlier special help or 'stimulation' begins, the more ability the child is likely to gain.

***IMPORTANT:* In this chapter we look at some of the causes of mental retardation and briefly describe 2 common forms (Down syndrome and cretinism). However, 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.**

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 in Indonesia, by Carolyn Watson, Christian Children’s Fund.)

Information on helping a child who is mentally retarded or developmentally delayed is in Chapters 34 to 40. Chapters 34 and 35 discuss **early child development** and ways to help or ‘stimulate’ a child to learn early skills (use of the senses, movement, and communication). Chapters 36 to 39 discuss **learning for self-care** (feeding, dressing, toileting, and bathing). Chapter 40 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 442 to 445. The needs and problems of mentally retarded children as they become sexually grown up are discussed in Chapter 52.

One important need that we do not include in detail in this book is education for retarded children. Some possibilities are discussed in Chapter 53, on education. But often special teaching methods and materials are needed. An excellent book is *Special Education for Mentally Handicapped Pupils.* For toys that help a child learn, see Chapter 49.

CAUSES OF MENTAL RETARDATION

There are many causes.

- **Often the cause is not known.**

- **Some children are born with a very small brain, or the brain does not grow or work normally.**

- **Sometimes there is a ‘mistake’ in the ‘chromosomes’ or the tiny chemical messages that determine what a child will be like *(inheritance).* This is what happens in Down syndrome.**

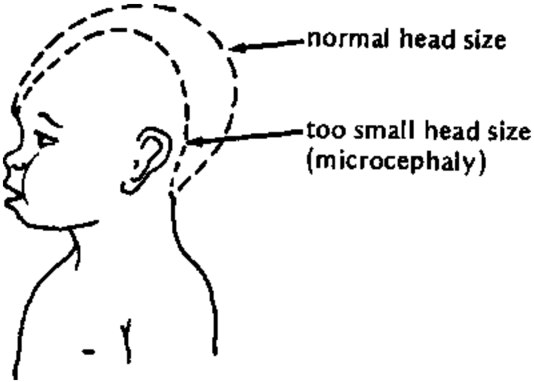
- **Sometimes a mother did not get enough of a certain food or mineral during pregnancy. (See “Cretinism,”)**

- **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, and include:**

- **German measles during early pregnancy**

- **meningitis (brain *infection*) from bacteria, tuberculosis, or malaria, most often during early childhood**

- **hydrocephalus, often with spina bifida**
- **head injuries**
- **other causes include brain tumor, poisoning from lead, pesticides, certain medicines and food, and some forms of muscular dystrophy or atrophy**



A child with microcephaly (small brain) is mentally slow and often also develops certain physical problems. For measurements of head size.

In many parts of the world, the most common causes 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.

Usually there is no treatment for mental retardation. Therefore, we often do not need to know the exact cause. Instead, we need to help the child develop the best he can. However, in some cases, certain medicines, 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.

Prevention of mental retardation is discussed with its different causes. See especially cerebral palsy, Down syndrome, and cretinism.

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. When a retarded person behaves in an abnormal way, it is usually because he has not learned the correct way to behave; he needs to be taught. The mentally ill person needs special help - perhaps from a spiritual healer or ‘psychiatrist’ (soul doctor). **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.**

DOWN SYNDROME

In many areas, Down syndrome - or ‘mongolism’ - is the most common form of mental slowness, or retardation. 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 (but *not all* the children have *all* these signs):

- At birth, baby seems floppy and weak.

- eyes slant

- 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.

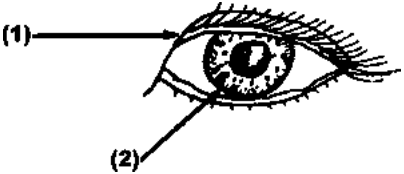
Figure

Figure

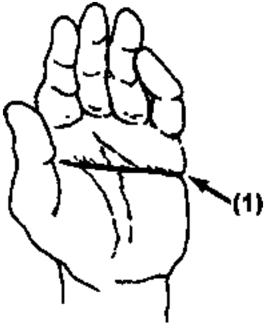
upward; sometimes cross-eyed or poor sight

- 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. (1)
- 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. (2)



Figure

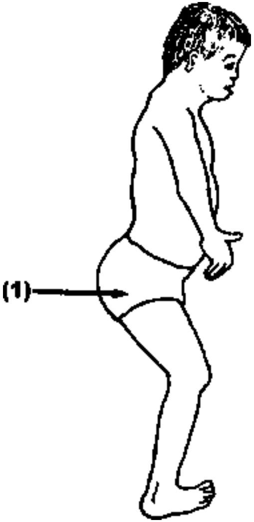


Figure

- short wide hands with short fingers. The little finger may be curved, or have only one fold.
- one deep

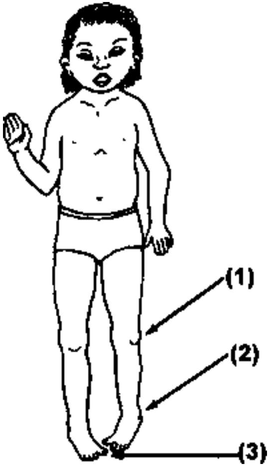
crease across the palm (sometimes in normal children, too) (1)

- short or small head, wide and flat in the back
- sometimes dislocated hips (1)



Figure

- flat face
- small nose, flat between the eyes



Figure

- short neck
- rounded shoulders
- short arms and legs
- kneecap slips to one side (1)
- ‘pigeon-toed’; flat feet (2)
- big toe far apart from other toes (3)

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).**
- **Check older children for hearing and seeing problems.**
- **One out of 10 has deformed neck bones which can slip and pinch the nerve cord in the spine. This may cause sudden or slowly increasing *paralysis* - or sudden death.**

Care of children with Down and other forms of mental retardation

Mental retardation in children with Down syndrome can be mild, 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 boys and girls are very friendly and affectionate, 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 important jobs. Sometimes they do repetitive jobs as well or better than other people.

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 40).

In one village, a young man with Down works hauling water from the river, a job he is happy and proud to do.

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 retarded child with respect. Unless the child is given understanding and extra help at school, in rural areas it may sometimes be better for the child with Down syndrome to 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.

A child with Down syndrome learns to remove pegs from a pegboard. Later she will learn to place the pegs. Photo from Teaching Your Down's Syndrome Infant by Marci J. Hanson.

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 41.**

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.

Figure

- **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, beans, 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

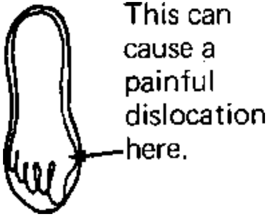
- **Check all newborns for possible *dislocated* hip, so that it can be corrected as soon**

as possible.

- **For the child whose big toe sticks out,**

Figure

do not use hard shoes that bend the big toe inward like this.



Figure

It is better to wear tennis shoes, or other soft shoes, or sandals.

Figure

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.

- 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 and it occurs more commonly with mothers under 20 and over 35 years of age. Women over 40 (or even over 35) may want to consider not having more children. Also, if a couple already has one Down child, the chance of having another is higher than normal (about one in 50).

In some countries a test (amniocentesis) can be done at about 4 months of pregnancy to see if the child will have Down syndrome. If so, the family can consider abortion (in societies where this is permitted).

CRETINISM (Hypo-Thyroidism)

Cretinism is a delay in both mental and physical growth that comes when a child’s body does not produce enough ‘thyroid’. Thyroid is a substance, or ‘hormone’, that controls a child’s growth and body functions. Without it, everything goes slower.

Thyroid is produced by a gland in the front of the neck. To produce thyroid, the gland needs iodine. Most people get enough iodine from water and food. But in some areas, especially in the mountains, the soil, water, and food have very little iodine. In an attempt

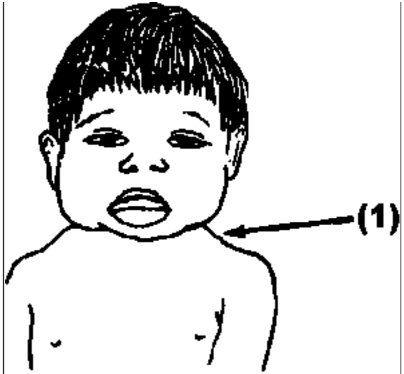
to obtain more iodine, the thyroid gland sometimes grows very large, forming a swelling called a goiter.

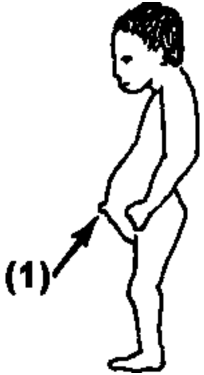
Figure

In areas where there is little iodine and a lot of people have goiters, cretinism is common. In these same areas, often many children have difficulty hearing or are somewhat retarded mentally. Although they do not show all the typical signs of cretinism, the cause is probably the same. Occasionally, in areas where goiter is not common, cretinism occurs for other reasons than lack of iodine.

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 newborn 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	Signs seen in both CRETINISM	Signs of DOWN SYNDROME (that are most useful in telling

 **Figure** • temperature below normal • thick, dry, cool skin	• puffy eyelids • flat base of nose between eyes • puffy face, hands, and feet • fatty swelling here (1) • grows very slowly. Increasingly short for age. • severe constipation (may go days without shitting) • often deafness • As child grows, knees may get large and painful.	AND DOWN • slow mental and physical development • widely separate eyes • round face, dull look • tongue sticks out of open mouth • short neck and limbs; wide, short hands • big belly and swayback • often hernia of the navel (1)	it from cretinism) • hair starts high on forehead • slant eyes with lid fold over inner corners  **Figure**



Figure

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 cerebral palsy, who is also blind, has fits, and is mentally retarded.

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 of in special care centers, or 'institutions'. Although in many cases it is better for the disabled child to stay at home with his 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 help 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 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 very 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, multiply disabled child to care adequately for the child, unless the community offers generous help and support.

Figure

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 some form of communication. Also, help her learn to interact with others in a way that her needs are met and her behavior is acceptable.**

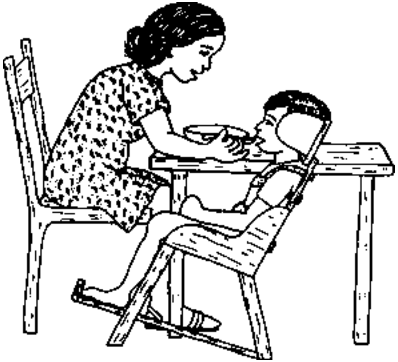
4. **To make caring for the child easier and more enjoyable for those who are responsible for her.**

Much of the information and suggestions in Chapters 34 and 35 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 small step at a time. Some of the suggestions included in Chapter 40, "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 65, 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 up 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.

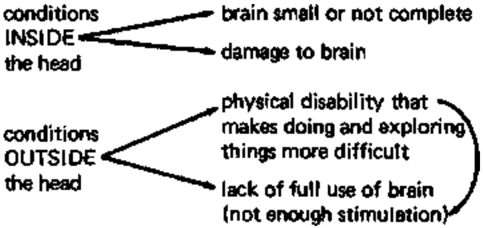
***CAUTION:* Breast feeding is healthier than bottle feeding. It is usually better to use a toy or rattle to draw the child’s attention rather than a bottle.**

C. Helping the Child Whose Mind and/or Body are Slow to Develop

Chapter 34: 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.

CAUSES OF SLOW MENTAL DEVELOPMENT



Figure

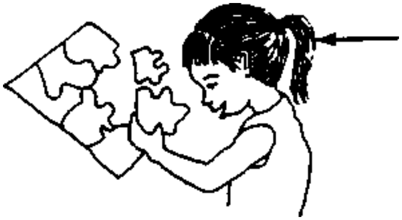
In this chapter we see how a child’s early development also depends on factors outside the child’s head - on the opportunities a child has to use his senses, mind, and body to learn about the things and people around him. We look at the stages or steps of normal child development, and at ways we can 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 and 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 the 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).



Figure

A CHILD'S MIND, LIKE A CHILD'S BODY, NEEDS EXERCISE TO GROW STRONGER

Figure

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 ways to help their child develop more

fully.

CP

ENRIQUE’S STORY

Enrique 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.

Enrique’s mother loved him and cared for him as 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 village workers helped Enrique’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

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, Enrique grew increasingly withdrawn. At age seven - if his mother understood him correctly - he asked her for a gun to kill himself.

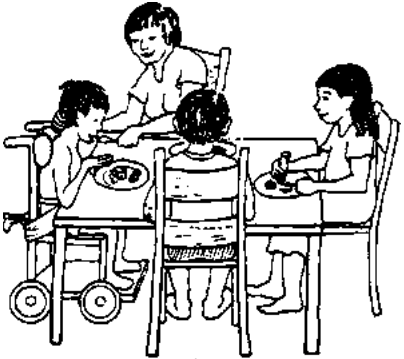
Soon after this, Enrique’s mother and his older sister took him to a team of village ***rehabilitation*** workers in a neighboring village. The workers realized that he would probably never have much control of his hands and legs. But he desperately needed to communicate more with other people and see 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.

Later, they added wheels to the chair.

With his new chair, Enrique 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

Figure

treated as one.



Figure

Every day Enrique’s sister and brother went to school. One day Enrique begged to go too, and they pushed him there in his chair. Soon he went every day, and began to learn to read. Enrique had begun to develop more control of his head. The village workers helped the teacher make a book holder attached to Enrique’s chair, and a head band with a wire arm so that he could turn the pages.

Figure

A happier and fuller life had begun for Enrique.

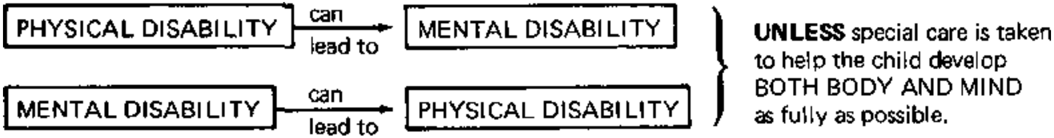
CP

Enrique's story shows how development of the body, mind, and senses all influence each other. Enrique 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 Enrique'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 joined. 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:

Enrique’s sister helps position him in his new chair.



Figure

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 Enrique’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, good food, and shelter. And they need the chance to explore their own bodies and the world about 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, 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 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.

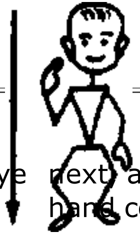
Every child develops in 3 main areas: physical (body), mental (mind), and social (communication and relating to other people). In each area, she develops skills step by step in a certain order. During the first year of life, normally a baby gains more and more

control of her body.

A child’s abilities develop in a particular order, one upon the other, like building blocks.

Body control develops progressively from the head down:

Development progresses from head to foot.



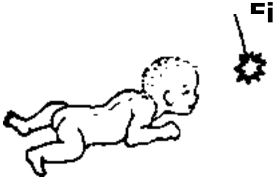
Figure

first, head and eye control

next, arm, and some hand control

then trunk (body) control, sitting, and balancing

and finally leg control



Figure

Figure

Figure

Figure

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 to shift her weight from side to side - skills she will soon need for standing 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 from 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 first we should hold her and speak to her a lot. Help her to reach out to touch and feel different things.

Figure

Later, we can encourage her to lift and turn her head, and then reach out, toward different sounds.

Figure

When she begins to sit, again we can help her to recognize different sounds and reach toward them.

Figure

When she begins to walk we can help her find her way with guide poles, and in other ways.

Figure

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:

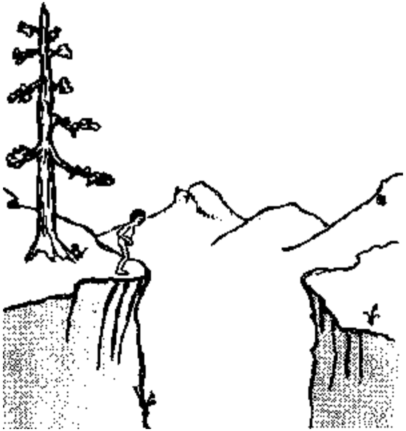
HEAD CONTROL → *TRUNK* CONTROL (SITTING AND BALANCE) → STANDING AND WALKING

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.

CP

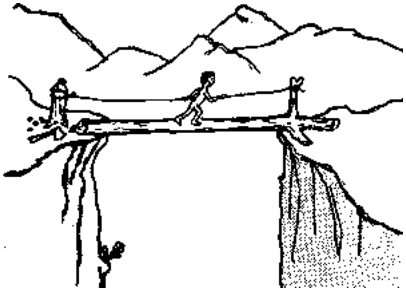
Trying to make your child walk before he is ready

is like telling him “JUMP NOW!”



Figure

when what you need to do is help him cross the gap-step by step.



Figure

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.

Figure

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. 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 shown does not mean he is backward or has a problem. Be sure to **look at the whole child.**

RECORD SHEET 6 (page 1)

EVALUATION OF A CHILD'S LEVEL OF *PHYSICAL* DEVELOPMENT

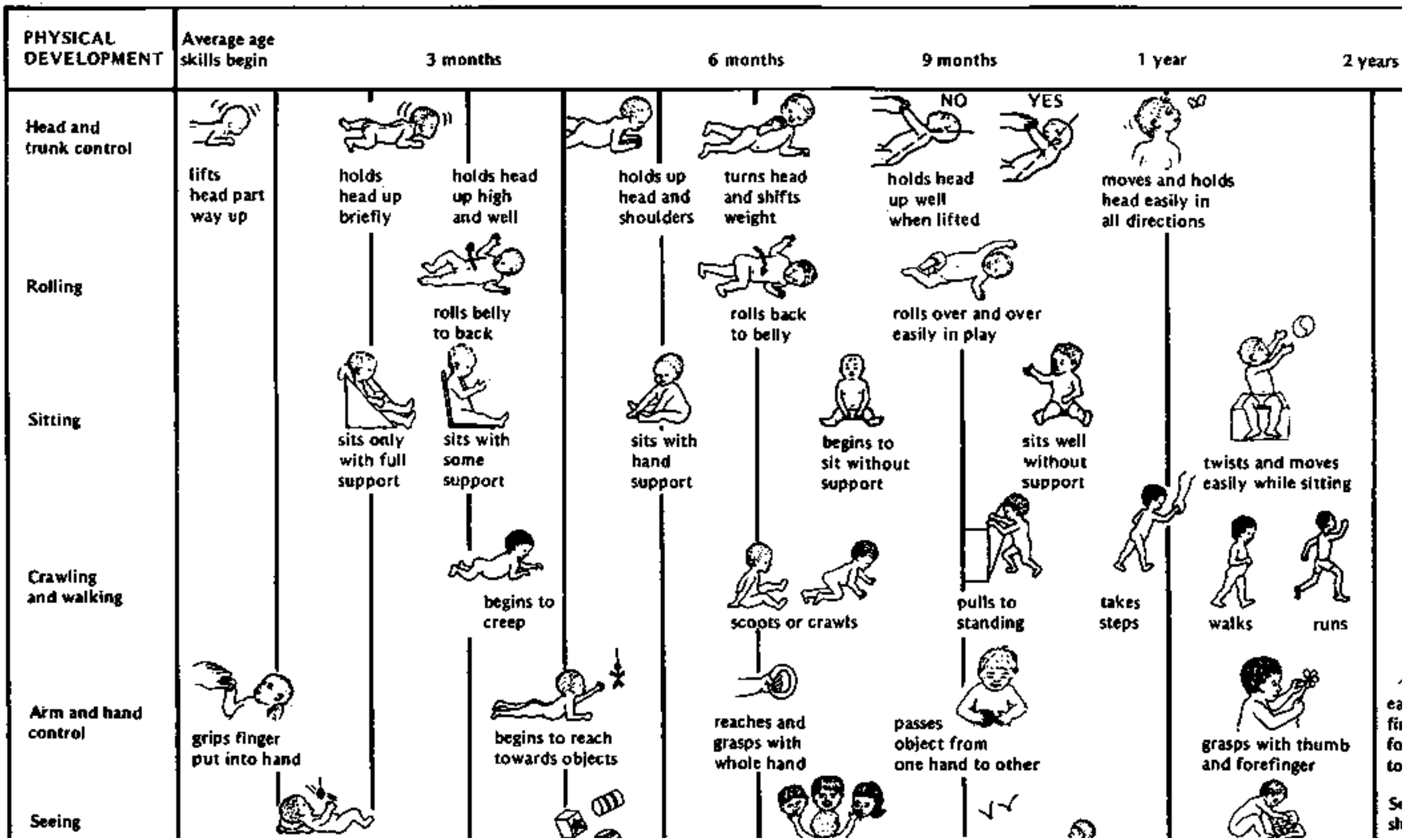
Note: **Although on these guides physical and mental skills are separated, the two are often closely interrelated.**

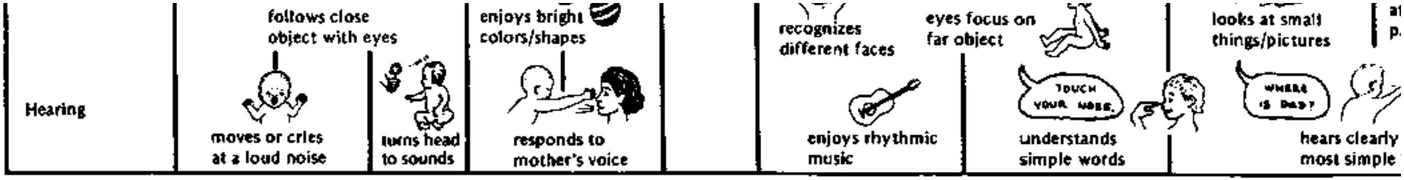
These charts show roughly the average age that a normal child develops different skills. But there is great variation within what is normal.

Name: ______________________

Birth date: ___________________

Date: _______________________



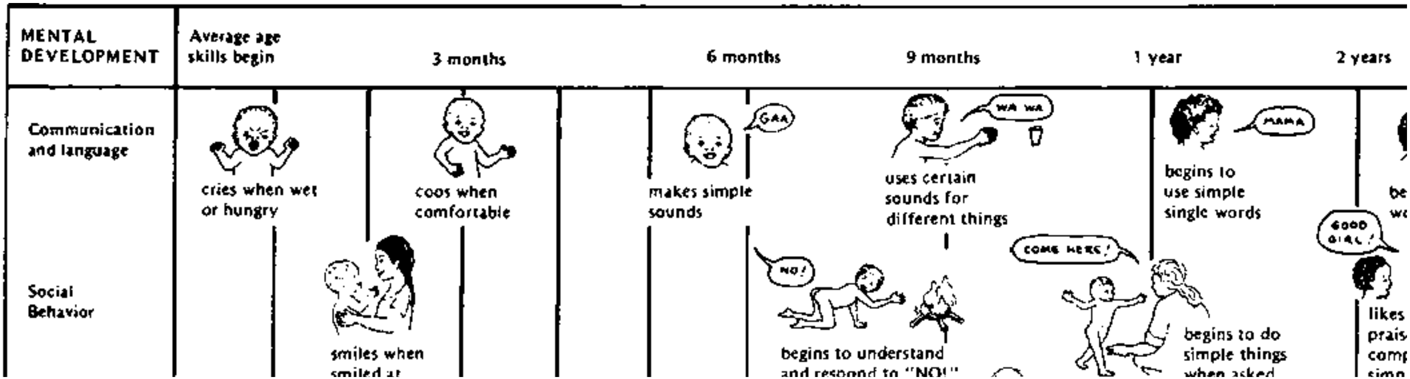


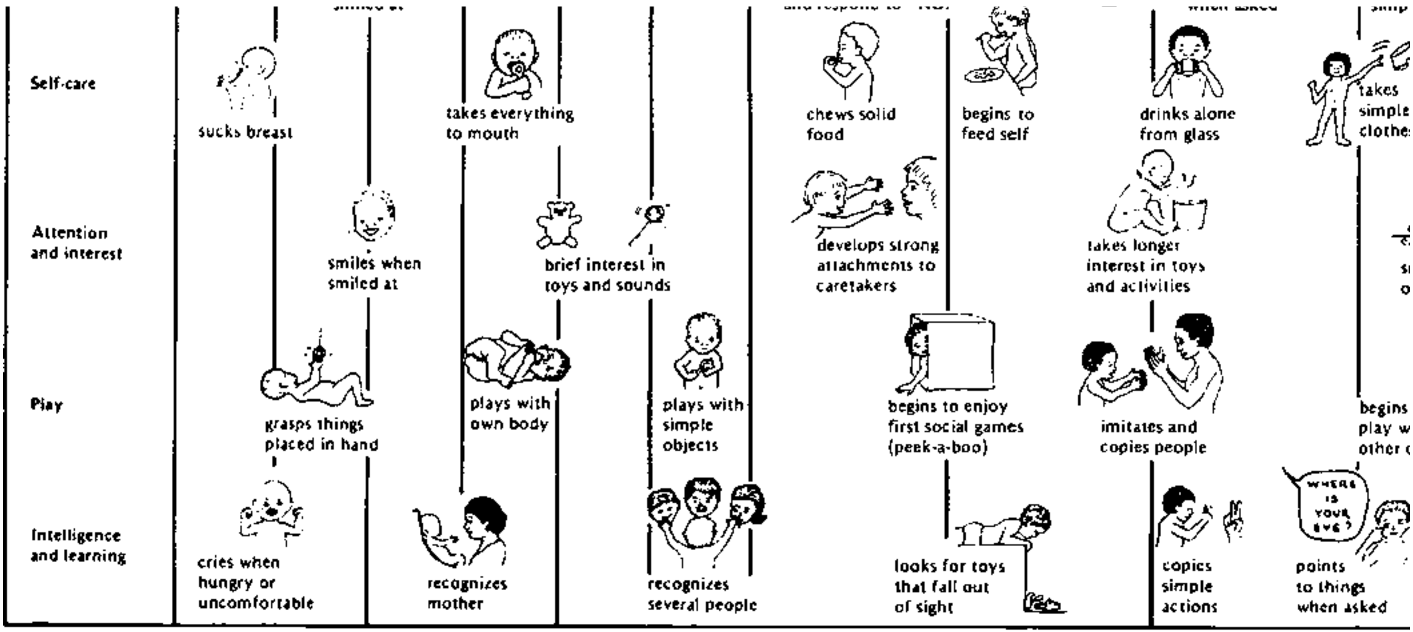
Figure

RECORD SHEET 6 (page 2)

EVALUATION OF A CHILD'S LEVEL OF *MENTAL AND SOCIAL* DEVELOPMENT

Name: ______________________
Birth date: ___________________
Date: ________________________





Figure

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.

How to use the Child Development Chart

The chart can be used to:

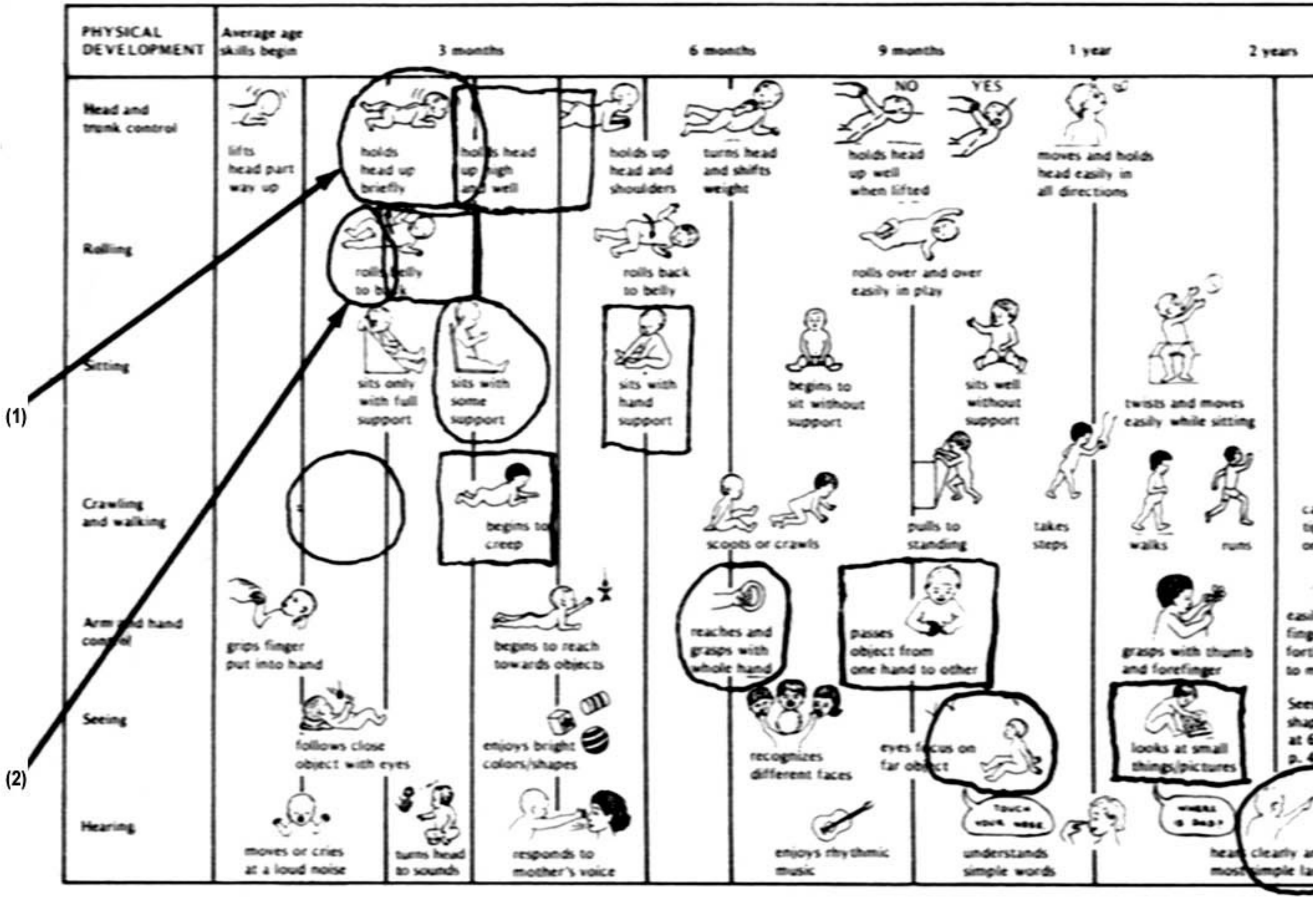
1. **find and record a child’s developmental level.**
2. **plan the next developmental steps or activities with which we can help the child, and**
3. **and record in which areas the child is progressing, and how much.**

CP

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. (1)

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’. (2)


PHYSICAL DEVELOPMENT
Average age skills begin
3 months
6 months
9 months
1 year
2 years
Head and trunk control
lifts head part way up
holds head up briefly
holds head up high and well
holds up head and shoulders
turns head and shifts weight
NO
YES
holds head up well when lifted
moves and holds head easily in all directions
Rolling
rolls belly to back
rolls back to belly
rolls over and over easily in play
Sitting
sits only with full support
sits with some support
sits with hand support
begins to sit without support
sits well without support
twists and moves easily while sitting
Crawling and walking
begins to creep
scoots or crawls
pulls to standing
takes steps
walks
runs
ca
ti
o
Arm and hand control
grips finger put into hand
begins to reach towards objects
reaches and grasps with whole hand
passes object from one hand to other
grasps with thumb and forefinger
easi
fing
fort
to m
Seeing
follows close object with eyes
enjoys bright colors/shapes
recognizes different faces
eyes focus on far object
looks at small things/pictures
See
shap
at 6
p. 4
Hearing
moves or cries at a loud noise
turns head to sounds
responds to mother's voice
enjoys rhythmic music
TOUCH YOUR NOSE
understands simple words
WHERE IS DAD?
hears clearly a
most simple la
(1)
(2)

Figure

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, and also to help her with rolling and twisting her body. Perhaps they can begin to work with sitting and creeping, 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.

Figure

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.

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.**

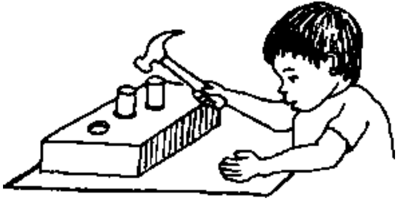
AREAS OF A CHILD’S DEVELOPMENT THAT CAN BE HELPED THROUGH EARLY STIMULATION AND LEARNING ACTIVITIES	
1. **Movement, body control, strength, and balance:** these will help the child move about, do things, play, and work.	 **Figure**
 **Figure**	2. **Use of the hands:** increased hand control, and coordination 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.	 **Figure**
	4. **Communication:** listening, understanding what is said,

 **Figure**	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.	 **Figure**
 **Figure**	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.	 **Figure**
The goals of an early stimulation program are to help the child become as able, self-sufficient, happy, and kind as possible.	

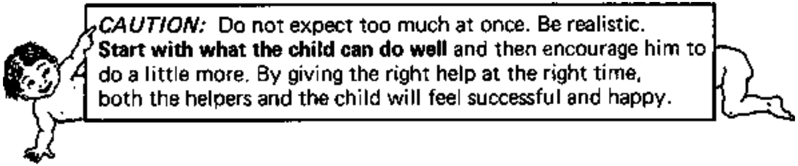
STEPS IN DESIGNING A PROGRAM OF SPECIAL LEARNING AND EARLY STIMULATION

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.



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.

Figure

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. 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 simple 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).

Figure

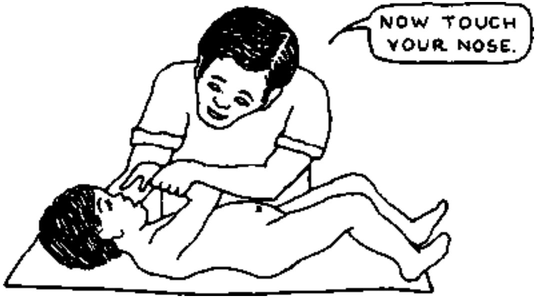
Explanation

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: "Too bad, better luck next time."

CAUTION: **Avoid giving sweets or food as prizes - especially if the child is fat.**

Figure

2. **Talk a lot to the child.** Using clear, simple words, say everything that you do with him.



Figure

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.

3. When you are helping a child learn a new skill, **guide her movements with your hands.**

Explanation

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,

Figure

and then to put her finger in her mouth.

Figure

After the child has learned to do this, let her do it by herself.

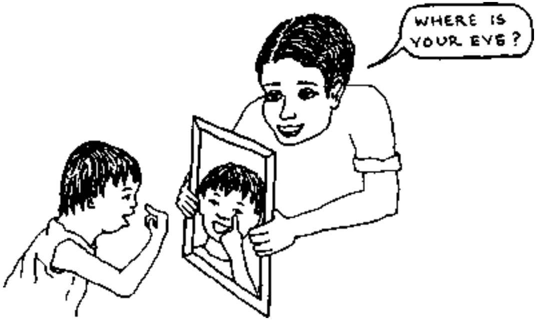
Figure

CP 4. **Use a mirror** to help the child learn about his body and to use his hands.

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!”

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 or knowing where they are. (This can happen in some forms of mental retardation, cerebral palsy,



Figure

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.

Figure

Explanation

Many retarded children (especially those with Down syndrome) love to copy or imitate the actions of others. This is a 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.**

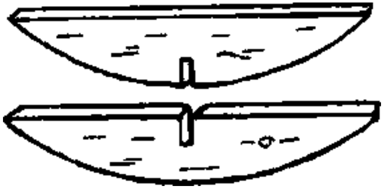
Explanation

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

Figure

When it gets too easy, put obstacles in the way - but do not make them too difficult.

7. **Make learning fun.** Always look for ways to turn learning activities into play.

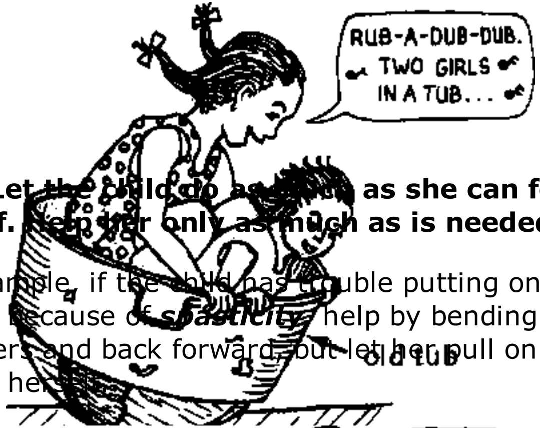


2 pieces of wood notched to fit together crosswise

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.

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.**



CP 8. **Let the child do as much as she can for herself. Help her only as much as is needed.**

For example, if the 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.

Figure

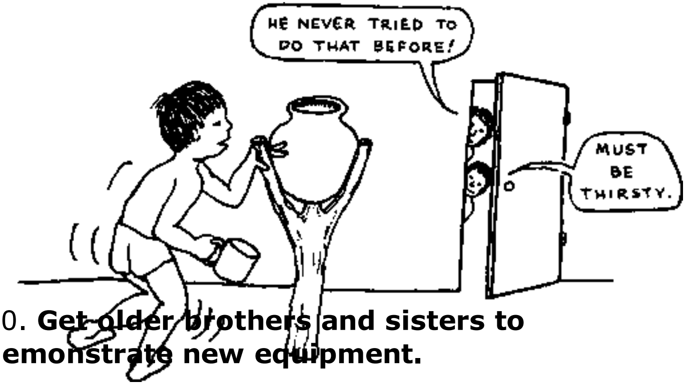
Explanation

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 - providing encouragement but assisting only in ways that let her do more for herself.

9. **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.



Figure

10. **Get older brothers and sisters to demonstrate new equipment.**

Figure

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 mentally retarded child learns the parts of a face by placing cut-out cardboard parts on a paper face. (Samadhan, Delhi, India)

Puppets are used to teach mentally retarded children in Samadhan (India). 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.

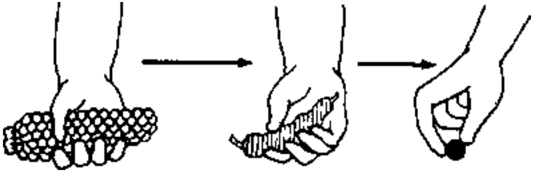
Chapter 35: Early Stimulation and Development Activities

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 or 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.



Figure

To decide which activities to begin with, start by using the charts on pages 292 and 293 to determine the developmental level of your child. Then look through pages 302 to 316 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.

Figure

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. Follow the suggestions on pages 296 to 299 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.**

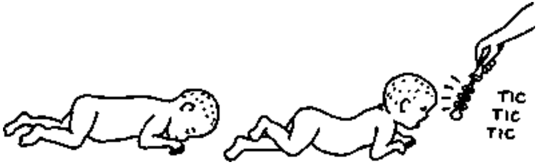
1) Head Control and Use of Senses

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 make strange or pretty sounds.



Figure

If the baby has trouble raising her head because of a weak back or shoulders, try placing a blanket under her chest and shoulders. Get down in front of her and talk to her. Or put a toy within reach to stimulate interest and

If she does not lift her head, to help her, put her like this. Press firmly on the *muscles* on each side of the backbone and slowly bring your hand from her neck toward her hips.

Figure

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.

movement.

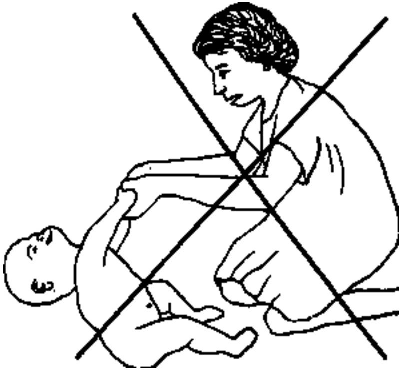
Some children can do more if they lie on a ‘wedge’.

Figure

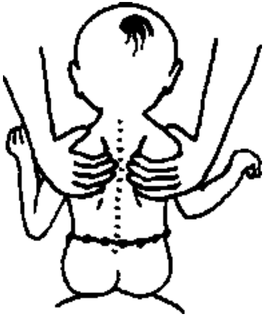
(CP) To help her develop head control when **lying face up,** take her upper arms and pull her up gently until her head hangs back a little, then lay her down again.

Figure

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”).



If a child with cerebral palsy stiffens as you pull his arms, try pulling the shoulder blades forward as you lift him up.



Figure

NOT LIKE THIS

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.

Figure

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

Figure

get it.

GOOD CARRYING POSITIONS

CP

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.

Figure

Figure

Figure

Figure

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) Rolling and Twisting

2. Activities to encourage rolling and twisting

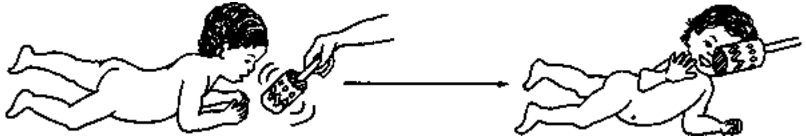
After a baby has fairly good head control, usually the next step in development is to roll over. Rolling involves sideways twisting of the head and body. Twisting, or rotation of the upper body on the lower body, must be learned before a child can learn to crawl and later to walk.

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.

Figure

Attract the child’s attention by holding a rattle or toy in front of her,

Encourage her to reach sideways for the toy,



Figure

then move the toy to one side, so the child turns her head and shoulders to follow it.

CP If she does not roll over after various tries, help her by lifting her leg.

Note: If the child has ***spasticity,*** you may need to help position this arm before she can

then move the toy upward, so that she twists onto her side and back.

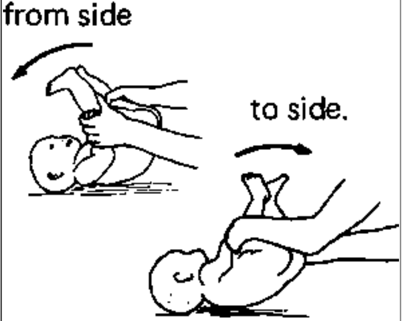
Also, help the child learn to roll from her back onto her side. Again, have her reach for a toy held to one side.

roll over. (1)

Figure

Figure

Note: If the child is very stiff, before doing other exercises or activities,	 	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.

		 **Figure**	
first help to relax him by swinging his legs back and forth,	or curl up the child in a 'ball' and slowly roll his hips and legs from side		
 **Figure**	 **Figure**		

***Remember:* THE FIRST RULE OF *THERAPY:* HELP ONLY AS MUCH AS NEEDED,**

ENCOURAGING THE CHILD TO DO MORE AND MORE FOR HERSELF.

3) Gripping, Reaching, and Hand-eye Coordination

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.

Figure

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.

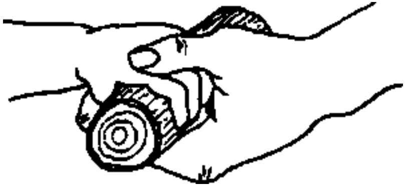
Figure

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!

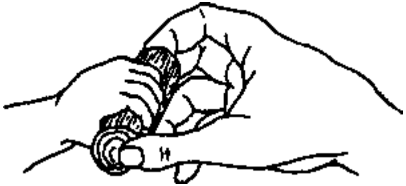
When the child opens her hands well, but has trouble holding on,

place an object in her hand, and bend her fingers around it. Be sure the thumb is opposite the fingers.



Figure

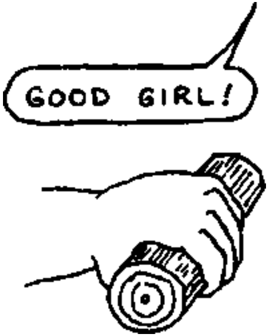
Gradually let go of her hand and pull the object up against her fingers or twist it from side to side.



Figure

When you think she has a firm grip, let go.

Repeat several times in each of the child's hands.



Figure

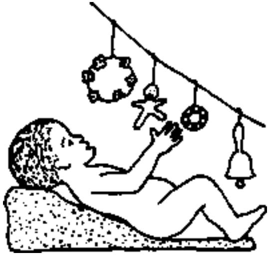
After the child can hold an object placed in her hand, encourage her to reach and grasp an object that just touches her fingertips. First touch the top of her

Encourage the baby to grasp by offering her rattles, bells, colorful toys, or something to eat on a stick.

hand - then place it below her fingertips.

Figure

Hang interesting toys, bells, and rattles where the child can see and reach for them.



Figure

This way the child learns to move her hand forward to take hold of a toy.

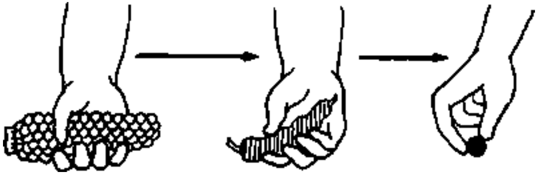
If the child shows no awareness of her hand, hang little bells from her wrist.

Figure

Also, 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

To help strengthen grip, play ‘tug-of-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.

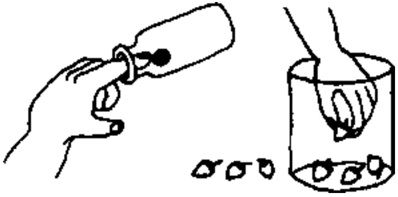


Figure

As the child gains more and more control, introduce toys and games that help develop **hand-eye coordination.** For ideas.

war' with the child - making it a fun game.

Figure



Figure

Make games of putting things in and out of boxes and jars.

Playing with toys and imitating the work and play of others helps the child gain more skillful use of his hands.

4) Body Control, Sitting, and Balance

4. Activities for body control, balance, and sitting

After a child gains good head control; he normally starts sitting through these stages.

sits when placed in a sitting position and held

Figure

sits, keeping balance with arms

Figure

balances with body while sitting, freeing hands for play

Figure

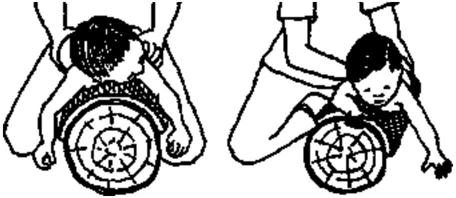
sits up alone from a lying position

Figure

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 a protective reaction 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.



Figure

Figure

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.

Figure

Figure

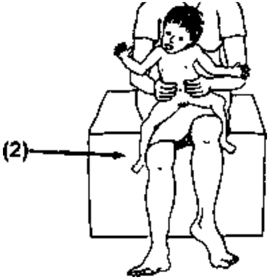
CAUTION: The child must be able to raise and turn her head before she can raise her body.

To help your child gain balance sitting, first sit her on your knees facing you.

Later, you can sit her facing out so that she can see what is going on around her.

Figure

Hold her **loosely** so her body can adapt to leaning (1)



Figure

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. (2)

You can do the same thing with the child sitting on a log.

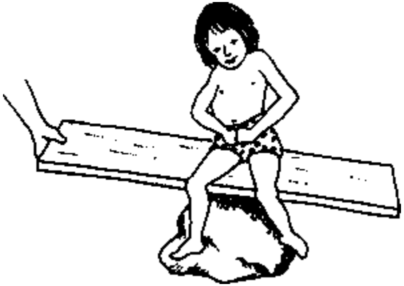
As he gets better balance, move your hands down to his hips and then thighs, so that he depends less on your support.

Figure

Give him something to hold so that he learns to use his body and not his arms to keep his balance.

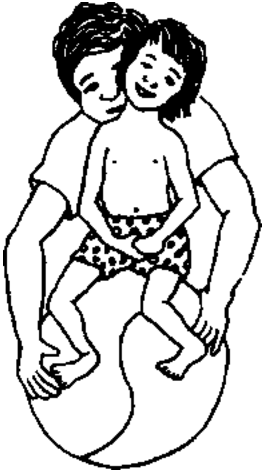
With an older child who has difficulty with balance, you can do the same thing on a 'tilt board'.

Figure



Figure

Or you can do the same on a large ball.



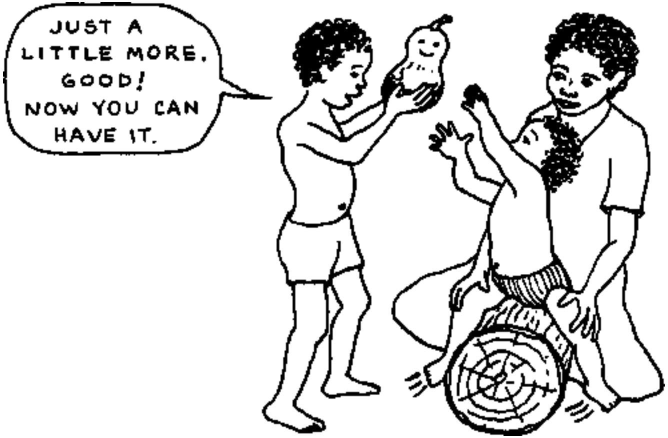
Figure

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.	Tilt it to **one side and the other** and also **forward** and **back**.

Note: You can also do these exercises 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.**	 **Figure**	**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.

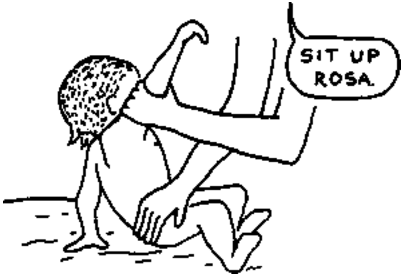
Figure



Figure

When the child can sit by herself, help her learn to sit up,

from lying on her back,



Figure

As the child starts to rise, push on the higher hip.

and from lying on her belly.

Figure

Press down and back on hip.

Figure

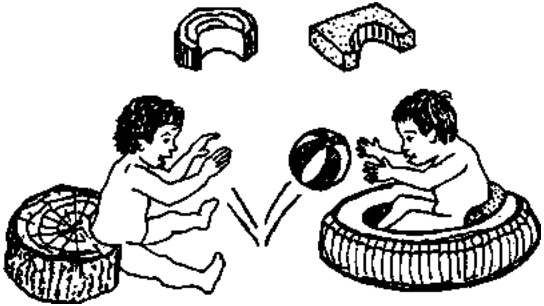
Help her roll to one side, rise onto

First help her lift her shoulders.

one elbow, and sit.

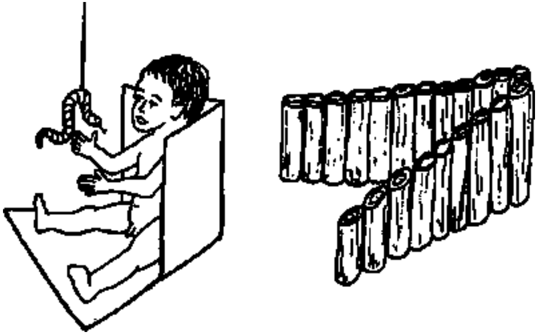
Help her to sit up herself. Do not pull her up. Praise her each time she does well, or tries hard. Help her less and less until she can sit up alone.

Some children will need seating aids to sit well. To help improve balance, the aid should be as low as possible and still let the child sit straight. Often, firmly supporting the hips is enough. Here are 2 examples:



Figure

For the child who needs higher back support, simple ‘corner seats’ can be made of cardboard, wood, or poles in the ground.



Figure

For more ideas on special seating and *positioning,* see Chapters 64 and 65. For sitting aids.

5) Creeping and Crawling

5. Activities for creeping and crawling

To move about, many babies first begin to **creep*,** and then to **crawl*,** or to **scoot** on their butt.

Figure

Figure

Figure

***North American therapists use these terms in the reverse way (creep for crawl and crawl for creep).**

***Note:* Some babies never crawl** but go directly from 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.

Figure

CAUTION: If the child has cerebral palsy, supporting the feet may cause legs to straighten stiffly. If this happens do not support her feet.

(CP) **If the child cannot bring her leg forward to creep, help her by lifting the hip.**

Figure

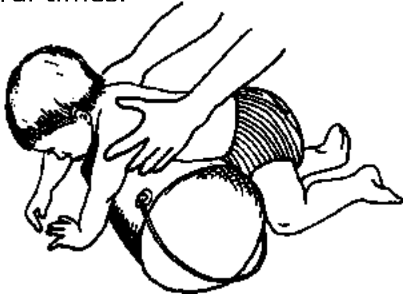
If the child has difficulty beginning to creep or crawl:

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.

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.

Figure

Encourage her to lift one hand off the ground and shift her weight to the other. Then help her to move forward.



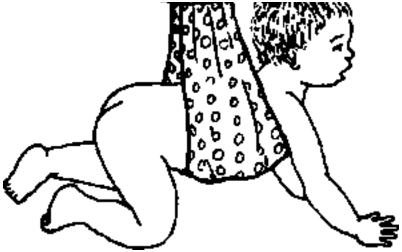
Figure

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.



Figure

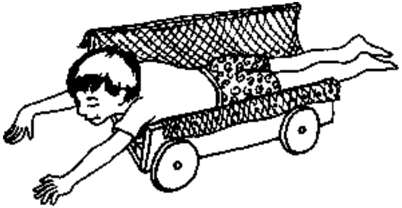
Figure

You can hang the child from a roof beam or branch, or a doorway, like this.

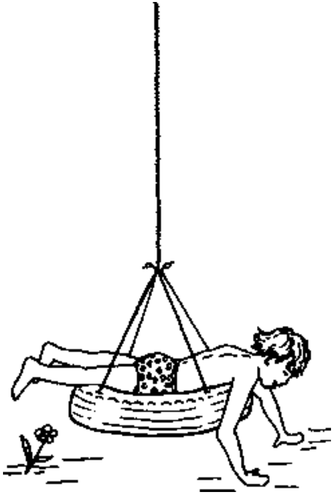
A child with spastic legs can hang with her legs supported to allow moving about using her arms.

Or make a simple ‘creeper’.

Figure

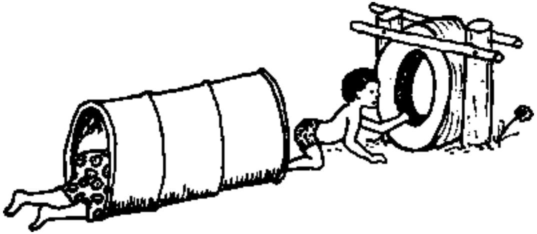


Figure



Figure

When the child has learned to crawl fairly well, have him play crawling games.



Figure

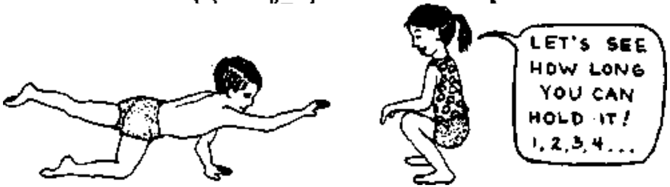
To help an older child with balance problems to prepare for walking, encourage him to **crawl sideways and backward.**

She can crawl up and down a small hill or pile of straw. This will help improve her strength and balance.

Figure

Also, have him hold one leg or arm off the ground and shift his weight back and forth.

Later, have him practice holding one arm and the opposite leg off the ground at the same time.



Figure

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.

A 'rocker board' is fun and helps balance.

At f **l up**
one l **k him**

Figure

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.

Figure

Figure

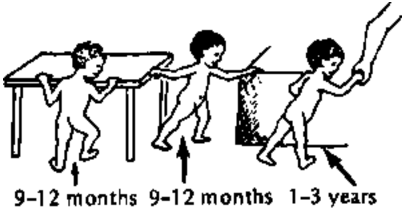
CAUTION: Do not do this in a child with spasticity whose knees bend a lot when she stands.

6) Standing, Walking, and Balance

6. Activities for standing, walking, and balance

Normally a child progresses through these stages:

bears part of weight automatically when held like this (standing reflex)	automatically ‘steps’ if tilting forward (stepping reflex)	sinks down when stood up,	stands holding on	pulls up to standing	steps sideways holding on	steps between objects	walks with 2 hands, 1 hand, and finally, no support



Figure

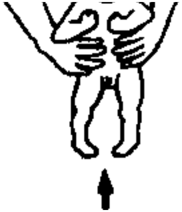


Figure
0-3 months

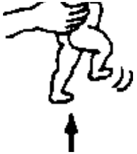


Figure
0-3 months

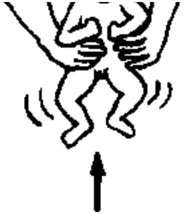


Figure
3-6 months

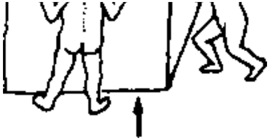


Figure
7-9 months

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.

Figure

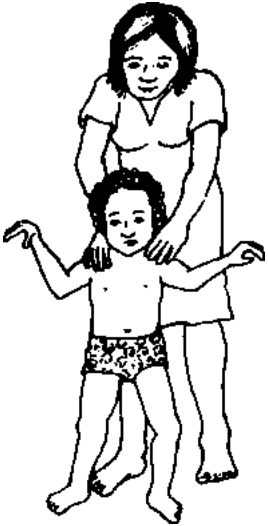
> ***CAUTION:*** **In children with spasticity, this activity may increase muscle stiffness. DO NOT**

DO IT.

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.

Move her gently from side to side, so that she learns to shift her weight from one leg to the other.

CP **As she gains better balance, you can provide a light support at the shoulders.**

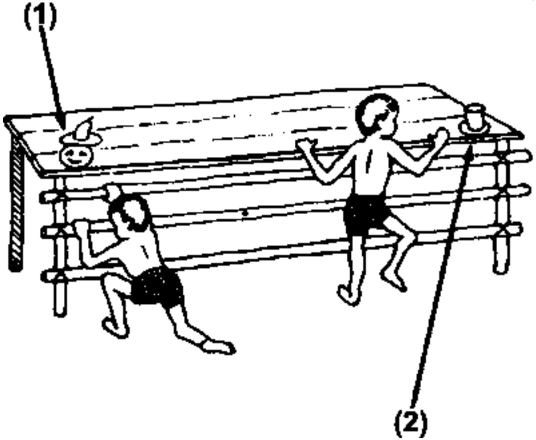


Figure

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. (1)



Figure

To encourage him to take steps, put something he likes at the other end of the table. (2)

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.

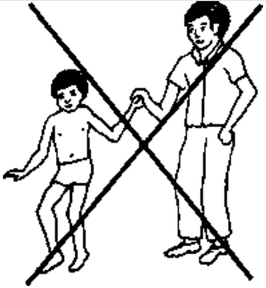
At first support the child while you do this. When his balance improves, do it without supporting him - but be ready to catch him if he falls.

Figure

Practice walking sideways and backward.

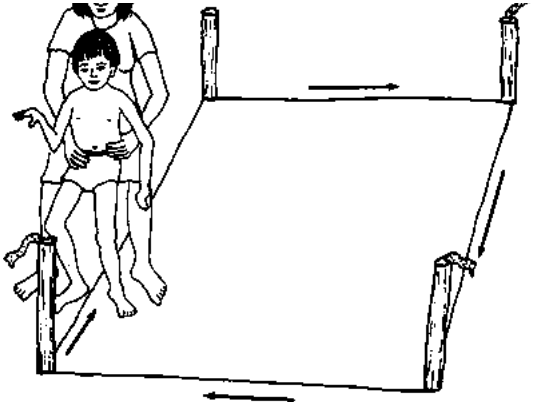
Note: Walking backward helps children who tend to walk tiptoe to bring their heels down.

Figure

It is better to hold a child:	
LIKE THIS	NOT LIKE THIS
 **His balance is centered in his body.**	 **His balance is off center.**

Support your child only as much as he needs, until he can walk by himself.

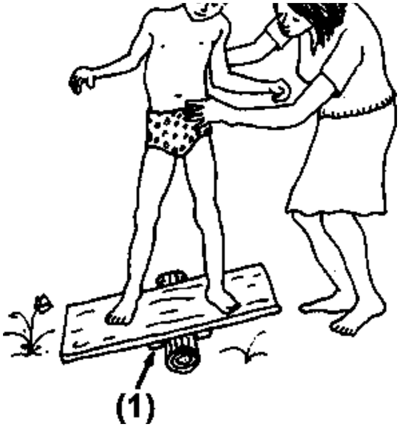
For the **older child** with poor balance, a homemade **balance board** will turn developing better balance into a game. Move slowly at first - especially with a child with cerebral palsy.



Figure

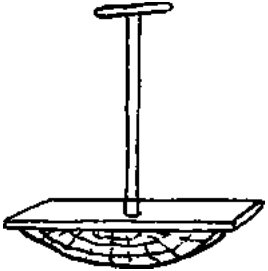
CP

Draw a square on the ground and help him to take steps forward, sideways, and backward. 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.



A balance board with a wide rocker is better because it rocks more smoothly.

Blocks to prevent rolling sideways. (1)

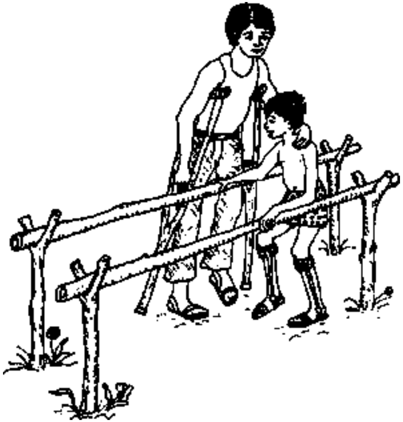


Some children will need a pole to hold onto.

Simple homemade **parallel**

Homemade **pushcarts** or **walkers**

bars can help a child with weak legs or a balance problem get started walking.



Figure

can provide both support and independence for the child who is learning to walk or who has balance problems.

Figure

A simple wooden walker with plywood wheels helps this developmentally delayed child begin to walk. (For designs of walkers)

7) Communication and Speech

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	makes 'happy sounds' - coos and gurgles	babbles - listens to sounds and tries to imitate	says a few words	begins to put words (and ideas) together

Figure

0-1 month

Figure

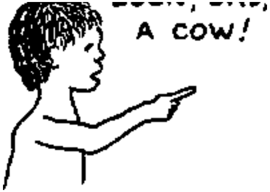
1-2 months

Figure

4-8 months

Figure

8-12 months



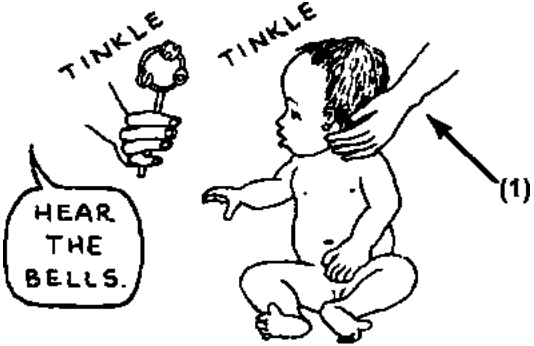
Figure

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.



If she does not turn her
the toy back so she can
move it away again.

'Or, gently turn her hea
sees what makes the sou
less and less - until she t
alone. (1)

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'.**

Figure

Understanding language depends not only on hearing, but also on watching lips and looks. So **speak to the child on her level.**

To get the child used to l **explain everything you him.** Use clear, simple w same ones each time. Na objects, body parts. Repe

Figure

A child understands word can speak them. Play **qu games** to help him lister he can answer your ques pointing, nodding, or sha

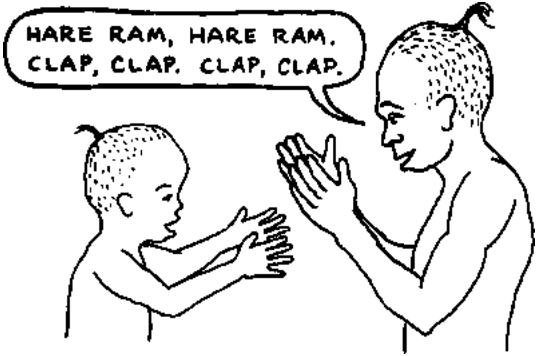
Figure

Figure

Repeat words. Ma requests. Reward s

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.

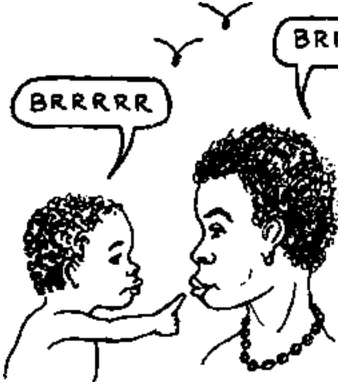
Imitate the sounds that b and have him copy the sa when you make them. Th similar to those sounds.



Figure

CAUTION*:* Encourage use of gestures, but not so much that the child does not feel the need to try to use words.

Also, imitate use of the
wide, close tight, stick ou
blow air, push lips in and



Figure

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.

Figure

Stroke or tap the upper lip, or gently press the lower lip several times.

Figure

Or, gently stretch the lip muscles. This may help the child to close his mouth.

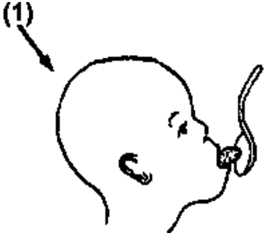
Figure

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.

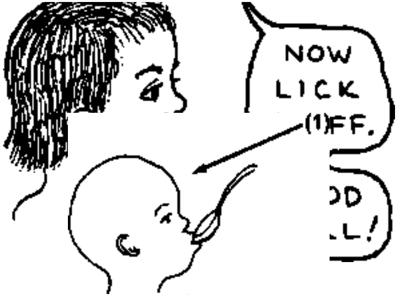
Figure

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. (1)



Figure



Figure

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. (1)

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:

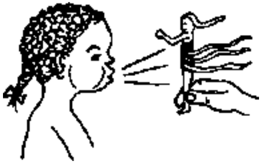
suck and blow bubbles through a straw

blow soap bubbles

Figure

Figure

blow air



Figure

blow whistles

Figure

CP

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.

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.

Figure

Figure

CP

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.”

If the child has trouble with controlling his jaw when

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.

When the child has difficulty pronouncing he tries to speak, try using **'jaw control'** with your fingers, like this. Have him repeat sounds that require jaw movement.

Figure

words, **do not correct her.** Instead, repeat the words correctly and clearly, showing that you understand.

Figure

***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. 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.

8) Early Play Activities and Toys

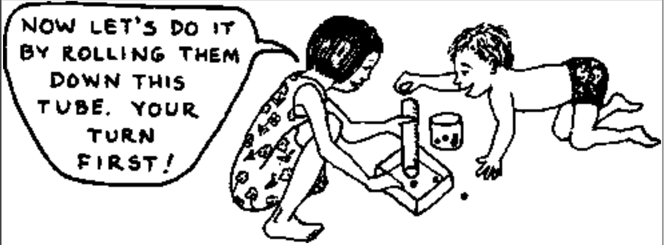
8. Early play activities and toys

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, it 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.**

 **Figure**	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?	 **Figure**

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.

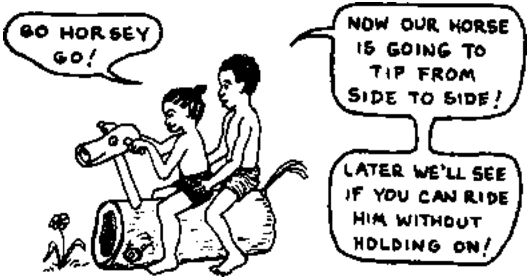
We do not talk much about play separately, because mostly it is not a separate activity. It is the best way to do almost any activity. For this reason, in this whole chapter - and book - we often give ideas for turning exercise, therapy, and learning into play.

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.

Figure

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.



Figure

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:

Figure

Figure

TOYS AND PLAYTHINGS TO STIMULATE A CHILD'S SENSES

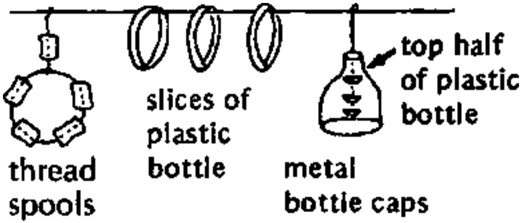
Play is more important than toys. Almost anything - pots, flowers, sandals, fruit, keys, an old horseshoe - can be used as a toy, if it is used in play.

Toys - or 'playthings' - offer stimulation for a child, both when she plays by herself and when she plays with others. Many simple things in the home can be used as toys, or can be turned into them.

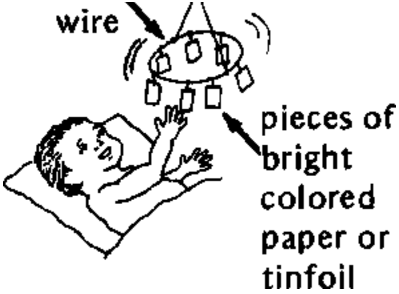
Hanging toys for baby to admire,

Caring for

touch, and handle can be made of many things



Figure



Figure

babies provides a learning experience that combines work and play for the child who is gentle.

Figure

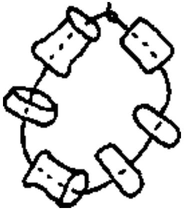
***CAUTION:* Take care that toys are clean and safe for the child.**

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

clay
string
chain
pulley
gears
rocks
beads
fruits
mud



Figure

flowers
dough

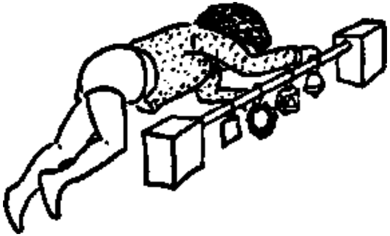
Toys for seeing

mirrors
colors
colored
paper or
tinfoil
daily family
activity
puppets
old
magazines
with

Fig

finger
puppets

swimming,
bathing
nuts and
bolts
toes and
fingers
seed pods
mushy
food
cloth doll
gourds
sand



Figure

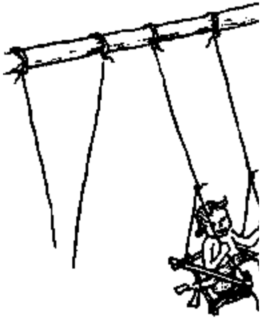
pictures
crystal glass
pieces
(rainbow
maker)
flashlight
(touch)

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.

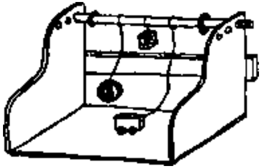
Figure

Toys for balance

swings
hammocks
seesaws
rocking
horses



Fig



Figure

Toys to taste or smell

foods
flowers
fruits
animals
spices
perfumes

Figure

Toys for hearing

Figure

rattles
guitar
flutes
drum
bells
bracelets
on
baby's

marimba
or
xylophone
wind
chimes
whistles
pet birds
animal
sounds
seashells
or other
echo toys
talking
laughing
singing

a pan as
a drum

wrist and ankles that tinkle when baby moves

tin can telepho

Figure

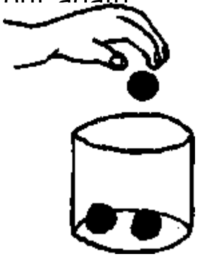
string or wire, stretc

TOYS TO DEVELOP A CHILD’S MIND AND HAND-EYE COORDINATION

Learning to fit things into things

Start simple - dropping	As the child develops, make things more complex.

objects into a jar, then taking them out again

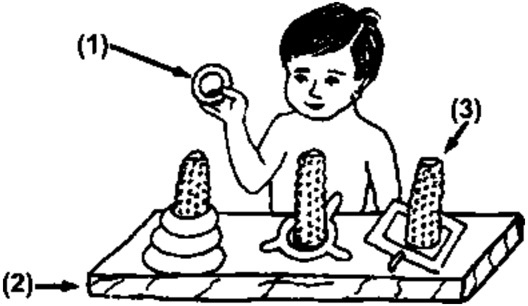


Figure

rings of wood, woven string, baked clay, old bones, or buckles (1)

base of wood or several layers of cardboard (2)

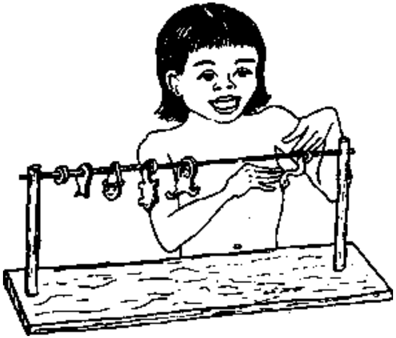
wood or corncob (3)



Figure

Note: Rings can be o different sizes, colors shapes so that the ch also learn to match t

To help develop controlled movement of the hands and arms, the child can move beads or blocks along a rod or wire.



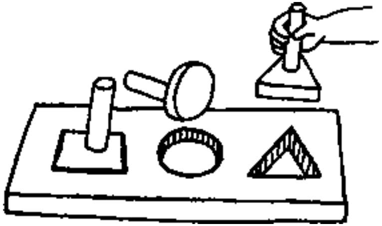
Figure

Using animals or funny figures makes the exercise more fun. Other children will be more likely to join in the game.

Figure

Matching games

The child can match objects of similar shape, size, and color.



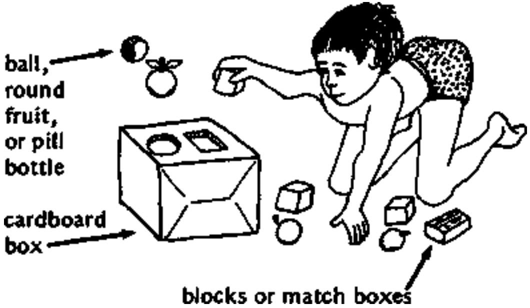
Figure

Start with simpler games with square or round figures.

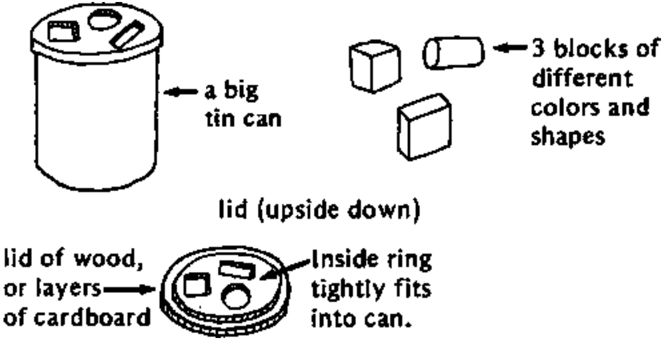
Small pegs glued onto cut-out pieces help develop fine hand control.

Figure

Then progress to more complicated games with different shaped figures.



Figure



Figure

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.

Figure

Many more ideas for simple toys are included in Chapter 49, "A Children's Workshop For Making Toys,".

D. Helping Children Develop and Become More Self-reliant

Chapter 36: Feeding

CP

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:

turn her head to seek the breast when her cheek is touched.

Figure

suck and swallow,

Figure

and cry when hungry.

Figure

By a few months of age, the child learns to take solid food in her mouth and eat it.

Figure

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,").

CP

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.

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.

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.**

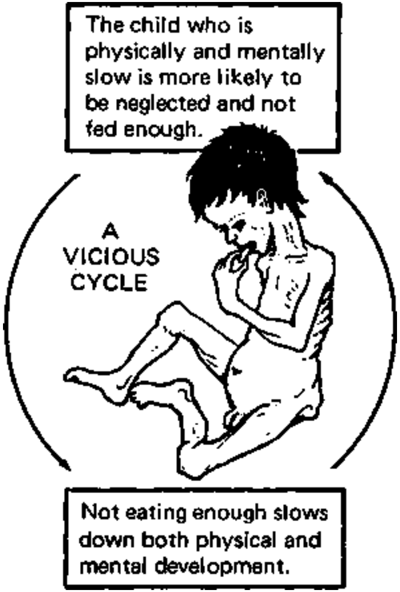
Good use of the lips and tongue when feeding is also important for future speech.

Figure

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.

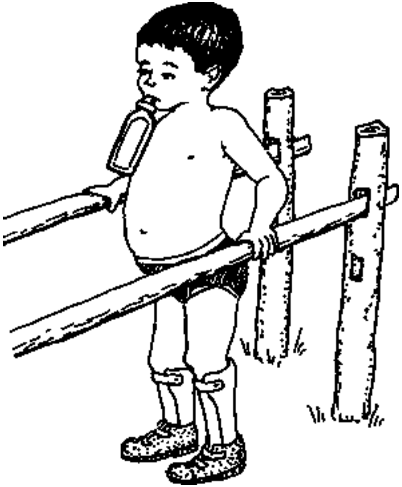


A VICIOUS CYCLE

WARNING: **Disabled children are often in greater danger of malnutrition than are other children.**

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.



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'.

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).

Normal: Lips, tongue and fingernails have a reddish, healthy color.

Anemic: Lips, tongue and fingernails, pale. Lack of energy. Tires quickly.

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!

REMEMBER: **A disabled child needs the same foods that other children of the same age need.**

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 protect the baby against infections.

Figure

Therefore, breast milk is especially important for children more likely to get *infections,* such as a child with Down syndrome or a child who often chokes on her food and might get pneumonia.

Breast milk is healthier for babies than other milks or 'formula'.

If the baby cannot suck, a mother can milk her breasts:

Figure

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

Figure

Continue breast feeding and also begin to give the baby other foods - juices and fruits rich in vitamins, mash of green leafy vegetables, beans (boiled, skinned, and mashed), peanuts (skinned and mashed), egg yolks, and other local staples such as rice, corn, plantains, or cassava.

Figure

Small stomachs need food often. Feed children under 1 year old at least **5 times** a **day** - and give them snacks between meals.

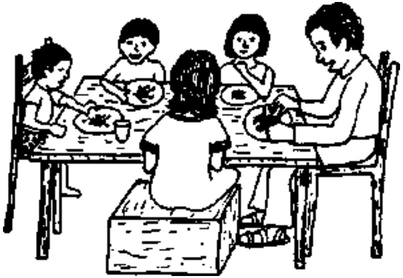
If the child has trouble eating solid foods, do not keep giving only milk or formula or 'rice water'. Even mother's milk alone is not enough after 6 months.

Figure

Mash or grind up other foods to form a drink or mush.

Figure

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.



Figure

Successful feeding involves the whole child

CP

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 bending hips enough to reach forward; poor hand-eye coordination; and difficulty holding things and taking them to his mouth. We must consider all these things when trying to help the child feed more effectively.

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.

CP

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.

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.

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

RIGHT

WRONG

Positions for feeding with a bottle, spoon, or finger are like those for breast feeding.

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.

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.

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.

WRONG

But this may choke him, and it does not help him learn to suck well.

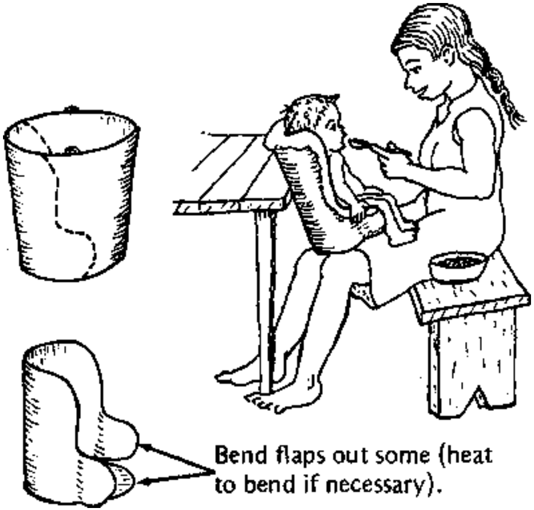
RIGHT

If possible, have baby hold bottle.

RIGHT

foot life to keep the baby’s knees higher (1)

A simple ‘baby seat’ can help the baby hold a good position while eating. Here is one idea using an old plastic bucket.



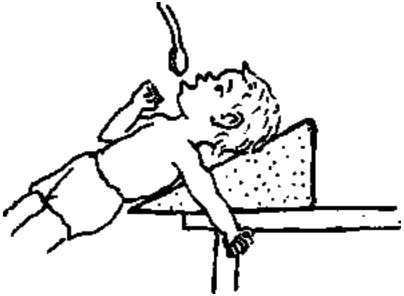
Bend flaps out some (heat to bend if necessary).

Figure

CP

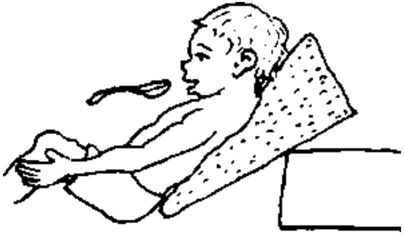
REMEMBER: When feeding a child with cerebral palsy,

giving food **from above** often causes the head to press back and body to stiffen. It makes swallowing difficult.



WRONG

Giving food **from in front** helps stop stiffness and makes eating and swallowing easier.



RIGHT

For other seating ideas.

HELPING CONTROL MOUTH FUNCTION

CP

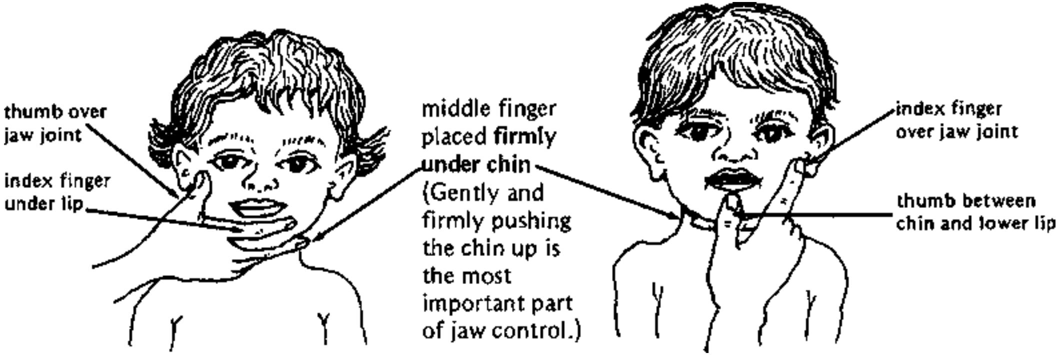
The child may also need help in improving the sucking-swallowing reflex, and her ability to eat from a hand or spoon and to drink from a cup. Sometimes these can be improved by

using what is called ‘jaw control’.

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



Figure

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.

CP

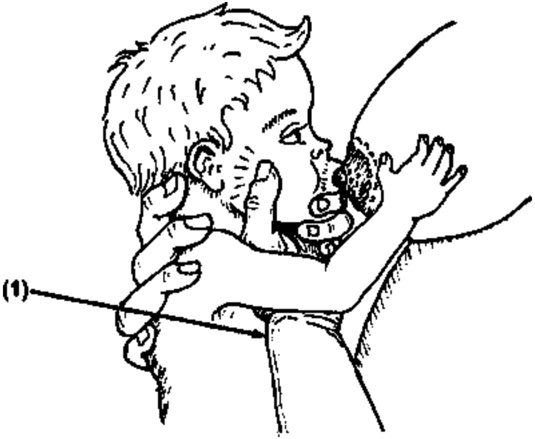
Good positioning together with jaw control will help with several problems common in cerebral palsy, such as pushing the tongue forward, choking, and drooling (dribbling). As

mouth control improves, gradually lessen and finally stop jaw control.

For more suggestions for controlling drooling and improving use of the lips and tongue, see the section on developing speech.

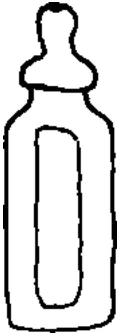
CP

For the child who has difficulty breast feeding (or bottle feeding), as you apply jaw control try bringing her cheeks forward with your fingers.



Figure

At the same time, push gently against the child’s chest with your wrist. (This may help the child who tends to stiffen backward.) (1)



Figure

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.

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, (1)

Figure

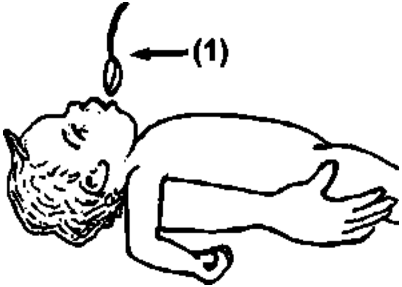
RIGHT

not from the side, (1)

Figure

WRONG

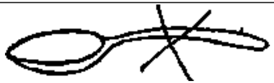
and not from above. (1)



Figure

WRONG

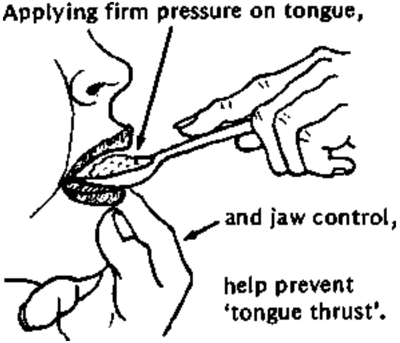
	YES

 **Figure**	
The best spoon is rounded and shallow.	
 **Figure**	NO
Not deep because this makes it hard for the lips to get out the food.	
 **Figure**	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.



Figure

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 the mouth and cannot push it out.

WRONG

If eating with fingers is the custom, or 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.

Figure

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, boiled corn, or mashed beans. You can also give small pieces of fruit, mashed greens and vegetables, and yogurt or soft cheese.

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, tortilla, or chapati. Help her close her mouth using jaw control.

Biting off can be encouraged by pulling slightly on a long thin piece of food. (1)

Or rub the piece of/food against the teeth before putting it between them.

Figure

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 to chew.** 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.

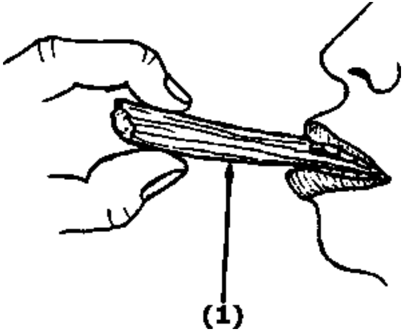
If the child has difficulty chewing and chokes on pieces of food, try this:

Cut a piece of clean, soft cotton cord, or braid

thin strips 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.

This method is completely safe. Because you hold on to the cord, the child cannot bite off pieces and choke on them. It is best to practice this at the beginning of a meal while the child is still hungry.

Figure



Figure

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. (1)

> ***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***).

Drinking

CP

Successful 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.

Figure

However, if he uses a plastic cup with a piece cut out, he can drink without bending his head back.

The cup should have a projecting rim.

Cut out a-space to fit around the child’s nose.

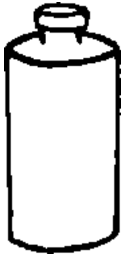
This way the child can drink in a better, more controlled position.


Figure


Figure


Figure

You can make a special cup from a plastic bottle.

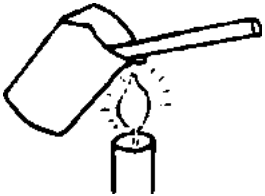


Figure

Cut it like this.


Figure

Gently heat the rim and gradually bend it out with a round smooth rod or stick.



Figure

Figure

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, maize mush, or yogurt.

Self-feeding

CP

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.

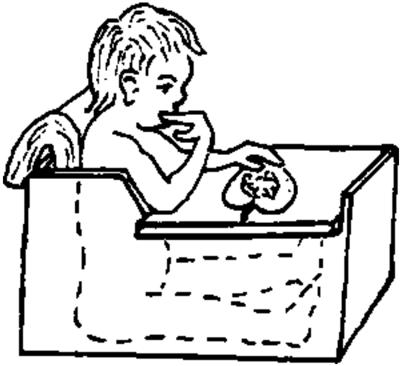
To prepare for self-feeding, encourage the child to play, taking his hands and toys to his mouth. Also, encourage him, when sitting, to balance while he uses both hands.

Figure

A child with poor balance or uncontrolled movements will at first need special seating adapted to her needs.

A HIGH CHAIR

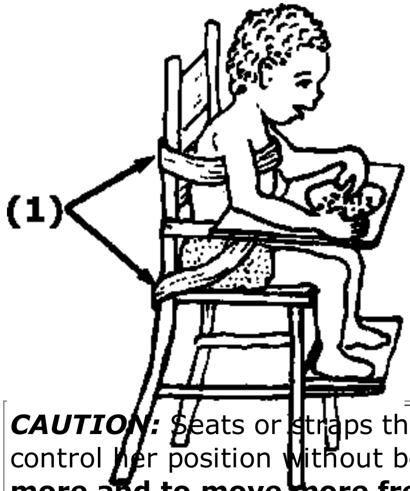
A CARDBOARD BOX SEAT



Figure

Figure

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).



Figure

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 Chapter 65.

Try one or more straps, to see what works best. (1)

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.

Figure

Figure

Figure

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 40, "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 until 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. (1)

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 disabled 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 MINUTE BISCUIT TRICK FOR DEVELOPMENTALLY DELAYED CHILDREN

by Christine Miles, Mental Health Centre, Peshawar, 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!”

Figure

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.

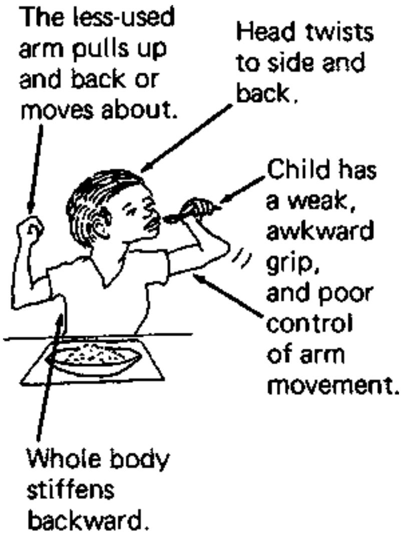
Figure

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



Figure

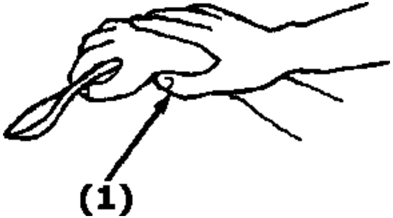
SUGGESTIONS

Help him learn to hold the spoon firmly.

Figure

WRONG

BETTER



Straighten his hand by turning it out ger from the base of the thumb. (1)

Sometimes you can help her with head control by gently pressing one hand flat against her chest.

Raising the table may make it easier for some children.

Figure

Where the custom is to eat sitting on the flo a child may be helped by making a low table out of a box.

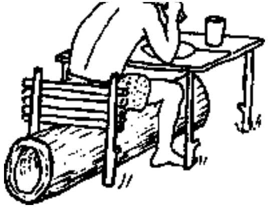
A child who has difficulty controlling her hand for eating may gain better control by resting her elbow on the table. (1)

When head and body are difficult to control, it may help to sit on a bench or log in a 'riding' position

Sometimes you can help the child avoi twisting to one side by bending the les used arm across the belly, and turning palm up. (1)

A child who has trouble controlling a cup with one hand can often better if the cup has two handles.

Ask a local potter to make one.



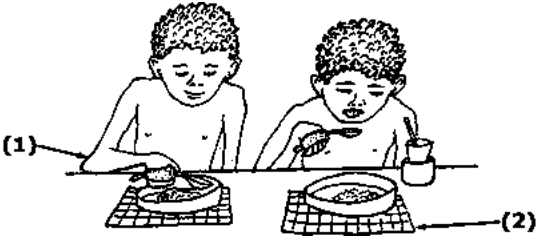
If he sits with a rounded back, it may help to support the lower back.

Figure

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.

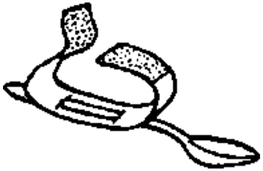
This boy, whose arms and hands are paralyzed, lifts his spoon by raising and lowering his shoulder. His forearm is on the table edge, so that when he lowers his elbow, his hand lifts. (1)



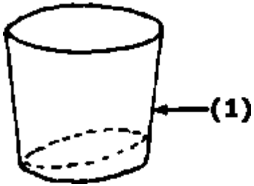
Figure

A non-slip mat under the plate can be made from strips of tire tube woven over a stiff wire frame. (2)

The spoon slips into a leather or rubber (tire tube) hand band.



Velcro (or buckle)



Figure

Figure

The special plate can be made from a small plastic bucket. (1)

To preventslipping, you can glue (with a waterproof glue) strips of tire tube on the bottom. (1)

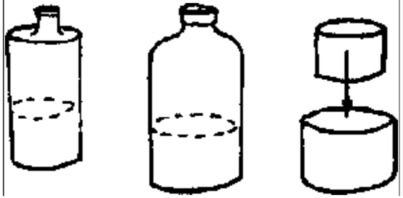
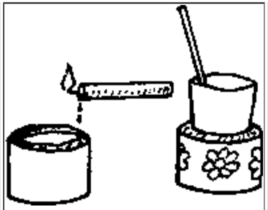
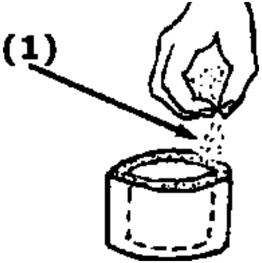
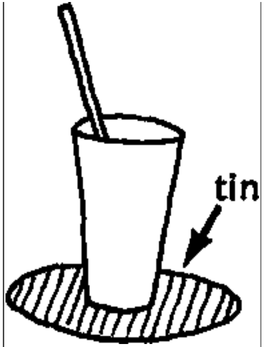
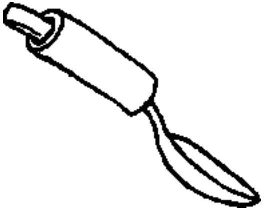
A non-spill cup holder can be made using 2 plastic bottles. 		 **Figure** Seal with wax or	Or, glue a plate or tin to the bottom of the cup.

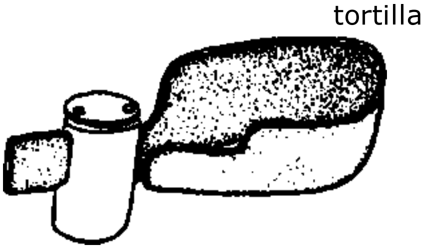
Figure	 **Figure** Fill space between containers with fine sand, plaster, or cement. (1)	waterproof glue.	 **Figure**

Spoon handles for easy gripping

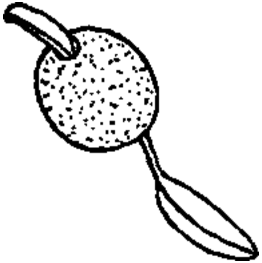


rubber tube

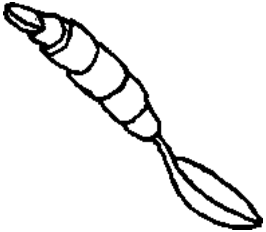
Tortilla or chapati holder



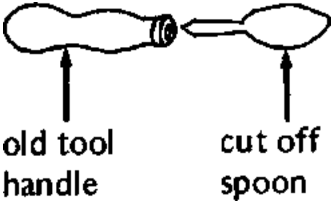
From UPKARAN Manual.



rubber ball

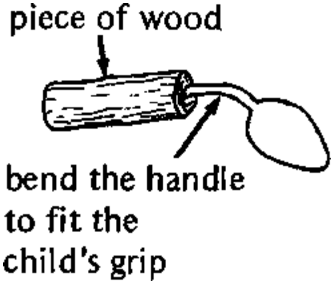


strip of tire tube (wrapped)



Figure

From UPKARAN Manual.

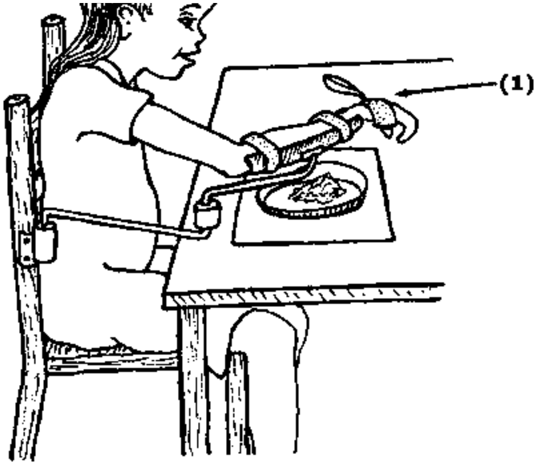


Figure

Swing-a-sling eating aid

This eating aid lets a child with very little strength in her arm feed herself. However, it must pivot smoothly but firmly at 3 points. It will take a skillful and imaginative craftsperson to make it.

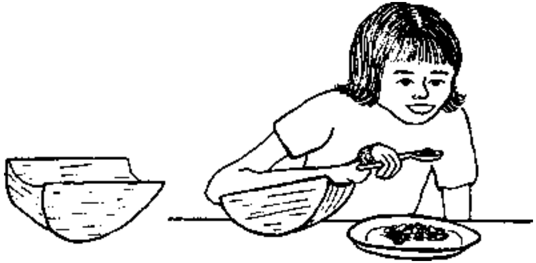
The spoon holder can also be adapted to hold a pen, brush, and other things. (1)



Figure

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.

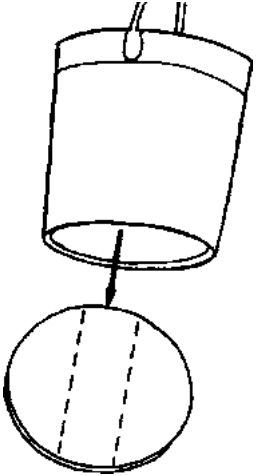


Figure

Or make it from the bottom of an old plastic (or metal) bucket.

Straps may or

may not be needed.



Figure

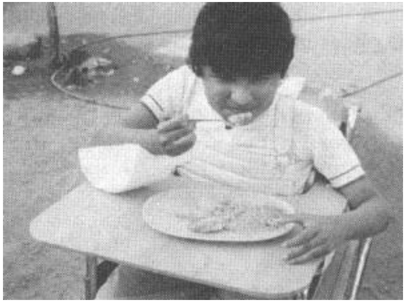
Figure

Heat the plastic along the lines with a hot strip of metal.

Figure

And bend it like this.

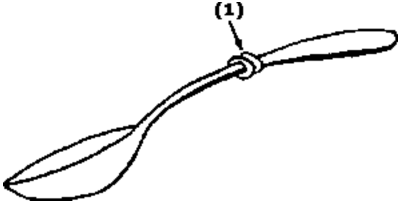
A boy with muscular dystrophy, whose arm is too weak to lift it to his mouth, eats with the aid of an arm rocker. This arm rocker, cut out of Styrofoam, took about 5 minutes to make.



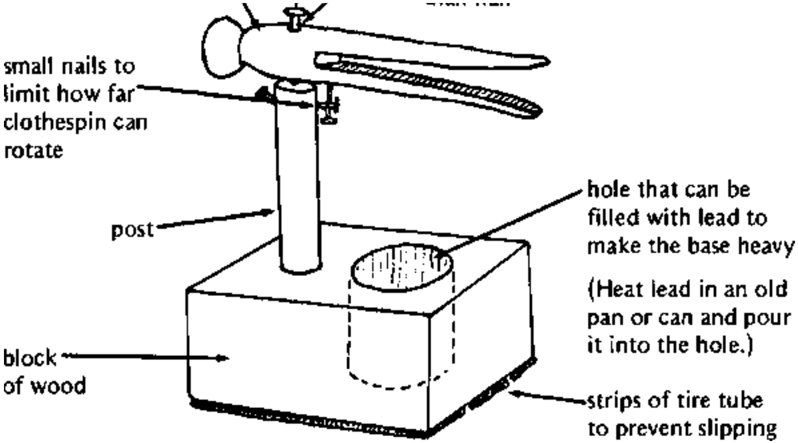
A boy with muscular dystrophy, whose arm is too weak to lift it to his mouth, eats with the aid of an arm rocker. This arm rocker, cut out of Styrofoam, took about 5 minutes to make.

Feeding aids for a child with no hand use

Put a ruubber band or clip on the spoon handle to keep spoon from slipping in clothespin. (1)



Figure



Figure

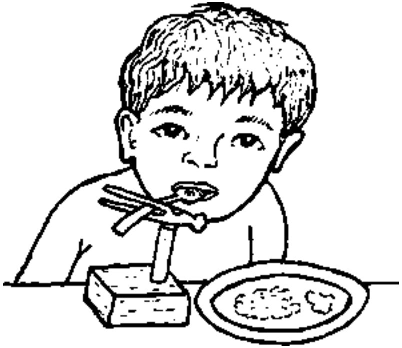
Pick up food holding spoon in mouth.

Slip spoon into clothespin.

With the lips, turn clothespin so that spoon enters mouth.

Figure

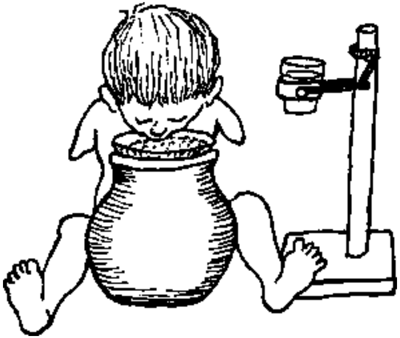
Figure



Figure

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.

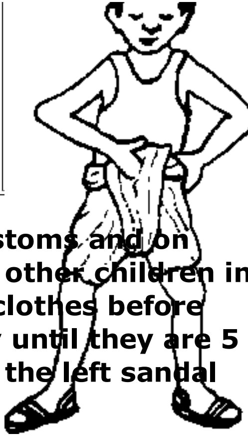
Use your imagination **to think of many other ways to help the disabled child eat and do other things for herself.**

Chapter 37: 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 y ol sh ad sa
 **Figure**	 **Figure**	 **Figure**	 **Figure**	 **Figure**		 **F**



Figure

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 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.

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.

Figure

POSITIONS FOR DRESSING

CP

Try dressing the child in different positions, to see what works best.

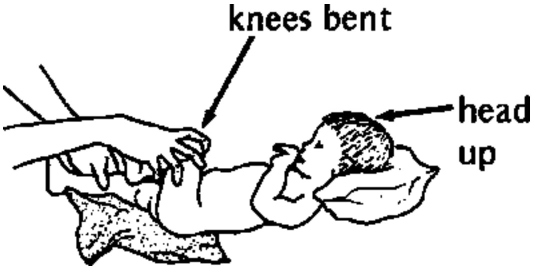
Body position is especially important when dressing a child with spastic cerebral palsy. Often his body tends to bend stiffly backward if he is dressed lying on his back.

It often works better to dress a child with ***spasticity*** with his hips bent forward.

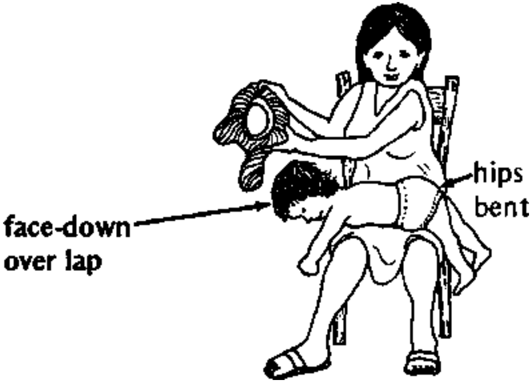
A bad position: (child's body stiffens backward)

Hand bends tightly. (1)

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.

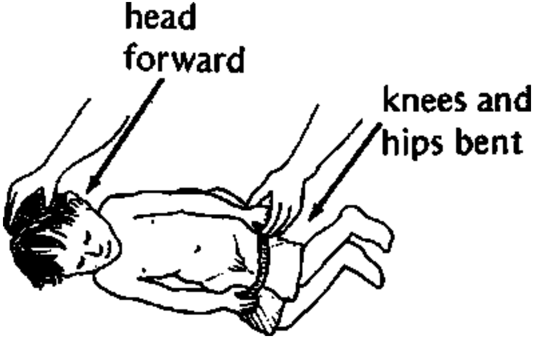


Figure



A good position:

Lying on the side is often a good position for a child with spa is beginning to dress himself. He may need to roll from one sid other to pull on clothes - but he should keep his knees, hips, a bent to avoid stiffening.

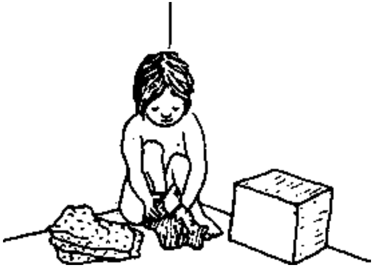


Figure

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.

first with help

If balance when sitting is still not good, or if the child tends to stiffen backward, try sitting in a corner to dress.



then alone

Sitting with the feet forward and knees apart
position for play and dressing. If legs press to
stiffly, try pushing the knee (1) out gently wh
press under the big toe. (2)

Figure

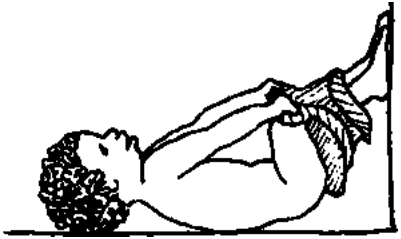
When a child with athetoid cerebral palsy tries to raise her arms or

Help the child find the position that allows the best control for dressing.

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.

Figure



Figure

Figure

Figure

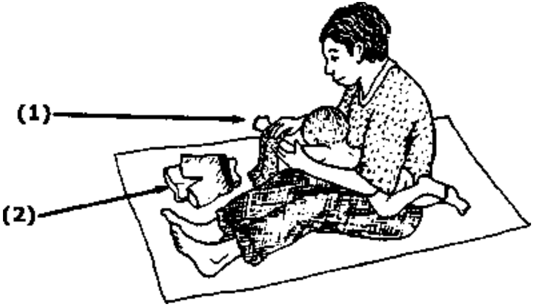
SUGGESTIONS FOR DRESSING

CP

- **If one arm or leg is more affected than the other, it is easier if you put the clothes first • on the affected side. (1)**

- **Put the clothes where the child can see and reach them easily, so he can help in**

any way possible. (2)



Figure

- **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.)**

Placing your hand on her lower back will help keep her hips and legs bent.

Or you can help keep her knee bent with your hand.

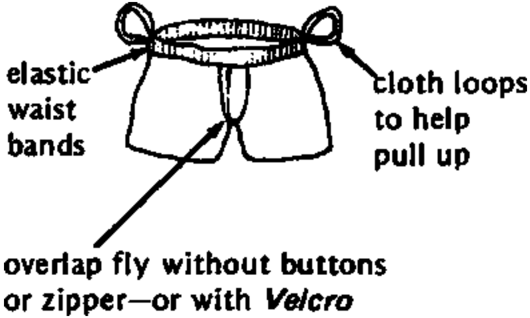
This keeps the legs relaxed and gives her better control.

- **If the legs straighten stiffly, bend them gently in order to put on pants or shoes.**

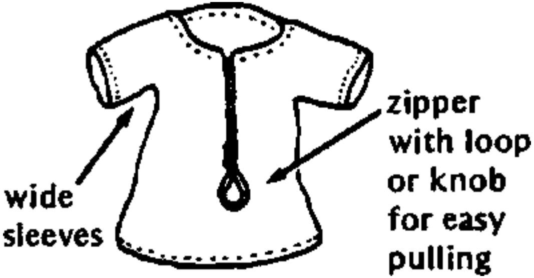
- **Begin any dressing activity for the child, but let him finish it for himself. Little by little have him do more of the steps. If he can do it all by himself, give him time. Do**

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. Here are some ideas:**



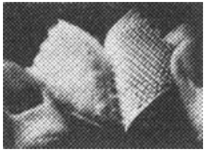
Figure



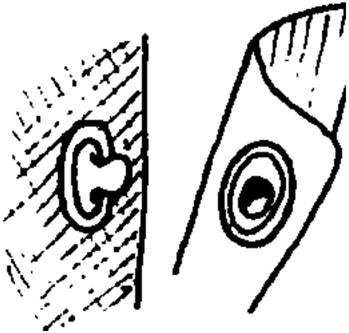
Figure

'Tube socks' (socks withou heels, that stretch to fit foot) are easier for the child to put on.

Figure



Velcro

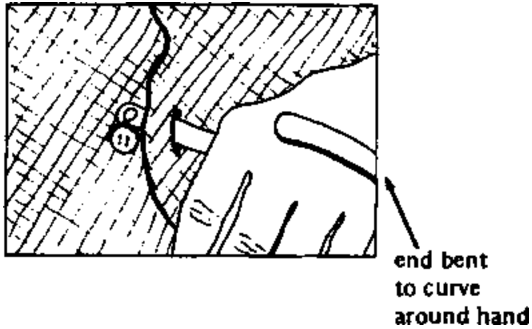


Figure

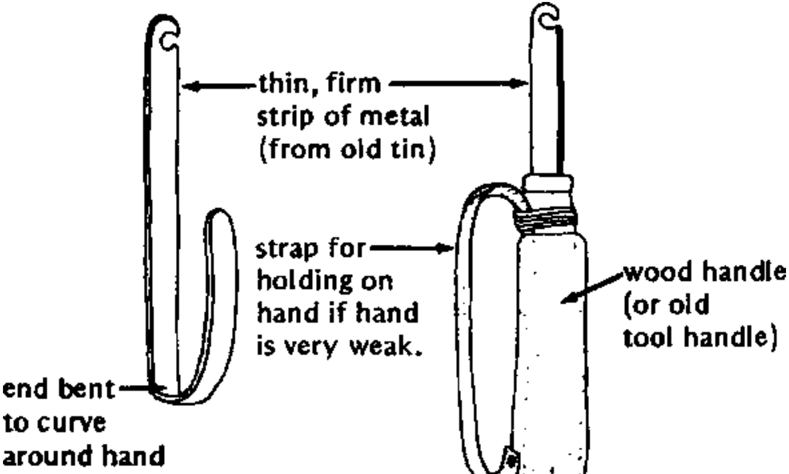
Press-together studs

(snaps) are easier to oper
and close than buttons.

- **For children who have poor finger control, make a simple tool to button and unbutton buttons.**



Figure



Figure

- **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:**

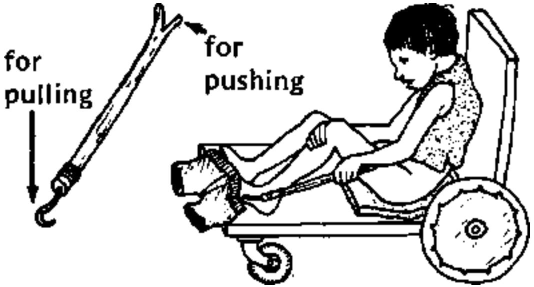
Sew a colorful bow on the front of her dress.

Draw half an animal on each sandal or shoe so that the 2 halves make the whole animal when she puts them on right.

Figure

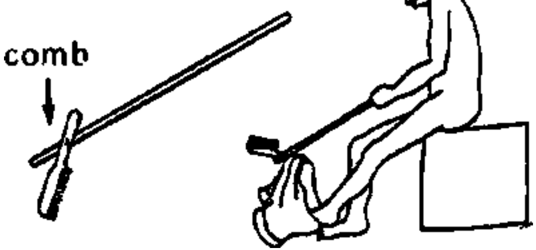
Figure

- **For the child who has difficulty reaching his feet, a stick with a hook may help.**



Figure

An all-purpose tool



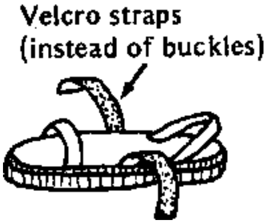
Figure

Ideas for shoes

- **For toes that claw up, or bend under, you can cut off the top of the shoe, or use a**

sandal.

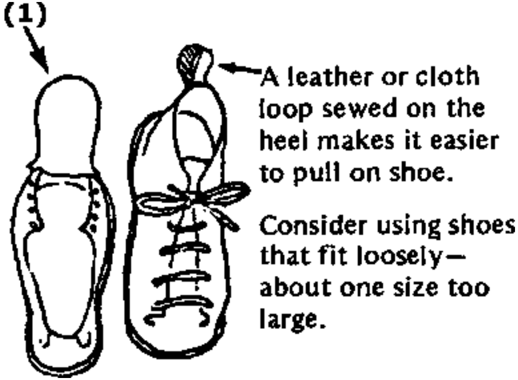
Figure



Figure

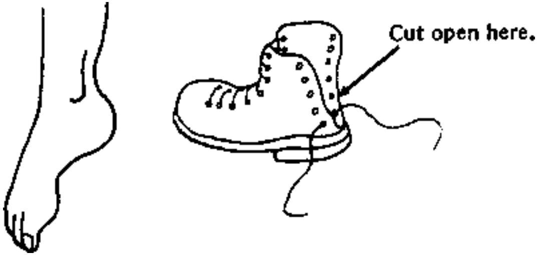
- **Tennis shoes or other shoes that open all the way down to the toes are easier to put on. (1)**

Figure



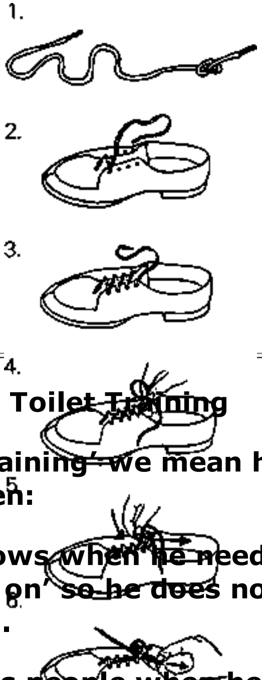
Figure

- **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.**



Figure

HOW TO TIE SHOES WITH ONLY ONE HAND



Figure

Chapter 38: 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 shit or pee (make 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.**

Figure

'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 2½. 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 deaf 10-year-old boy in Mexico 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 village *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 become completely toilet trained 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 2½. But in some children, training may need to be delayed to age 3 or 4, or sometimes later.

Most children learn to keep clean a long time before they learn to stay dry. However, because a child pees much more often than she shits, if training aims at ‘staying dry’, ‘staying clean’ usually follows.

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.*

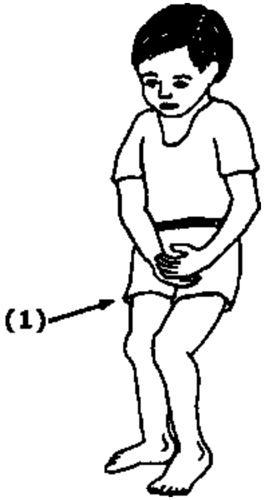
> *** These tests and many of these suggestions on toilet training are adapted from *Toilet Training in Less Than a Day.* Azrin and Foxx. Pocket Books, N.Y. 1974.**

- **Bladder control**

Does your child pee 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 pee? (The look on his face, holding himself between the legs, etc.) (1)



Figure

If the child does these 3 things (or at least the first 2) he probably has enough bladder control and awareness of peeing 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.

Figure

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.

SPECIAL PROBLEMS

CP

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.

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 40.

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 butt, various aids or ways must be looked for to help her become as independent as possible. These will be discussed on the next pages.

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 shits and pees. 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.

If the child 'goes', clap your hands, kiss her, show her what she has done, and let her know how pleased you are.

Figure

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 shits or pees 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 shits and pees, but because she is staying dry or dean. 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.

Figure

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!"

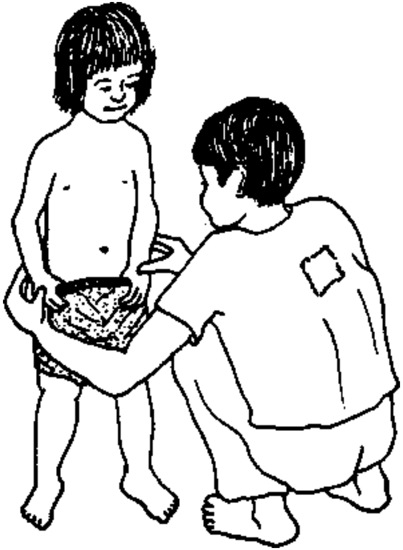
CAUTION: As a general rule, do not offer a child candy, sweets or other food as a reward for doing something right. This can lead the child to associate food with love or approval - and therefore to make constant demands for sweets. Avoiding food rewards is especially important for children whose disability 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.

DO NOT GIVE FOOD AS A REWARD TO CHILDREN WHO ARE FAT

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

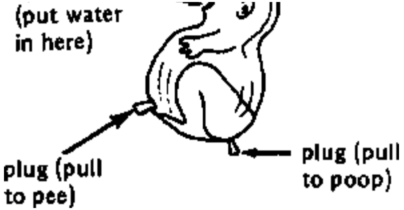
Setting an example is one of the best ways of teaching - especially if the example is set by persons the child loves, admires, and tries to copy. Even before children are old enough to be toilet trained, help prepare them by letting them watch their brothers and sisters use the pot or latrine. Tell them that when they are big enough they will be able to do it that way too.

Figure

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,

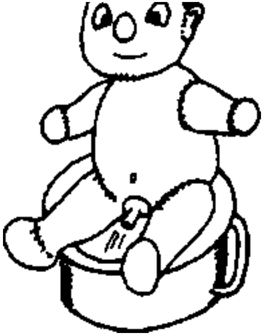
a gourd

or a baby bottle inside a homemade rag doll.



Figure

when lying down, no pee



when sitting up, doll pees

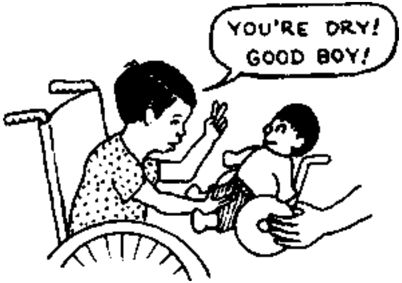
Show the child how the doll pees in the pot. Or better, ask your child to help you toilet train the doll. Be sure to include each step that will be needed for the child to become as self-reliant as possible. For example:

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 pees. 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.

Figure

Turn it into a game, but keep the focus always on toilet training



Figure

After the doll has finished peeing, 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.

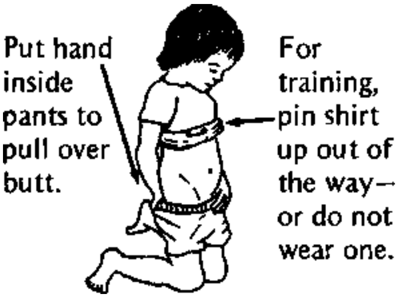
To repeatedly see real persons (not just dolls) *enjoy* and be rewarded for using the pot or toilet is especially important for a child who is retarded or who has language difficulty.

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:

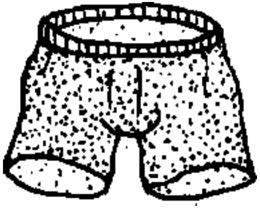
- **If the child has trouble pulling down pants or panties - use loose fitting clothing with elastic or '*Velcro'* waist band.**

Correct position of hands, for lowering pants



for raising pants

- **Use short ‘training pants’ made of towel-like material that will soak up urine.**



Figure

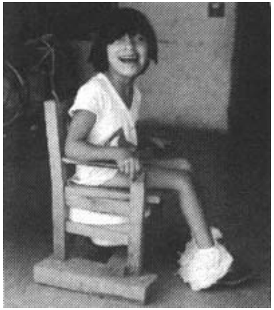
CP

- **For a child with cerebral palsy or spina bifida, it may be easier lying down - you might provide a clean mat.**

Figure

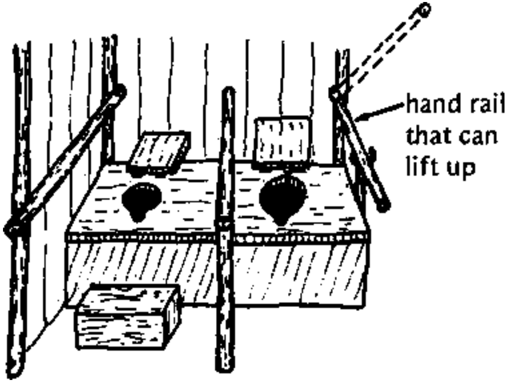
- **If people by custom squat to shit, and the child has trouble, a simple hand support can help.**

Figure

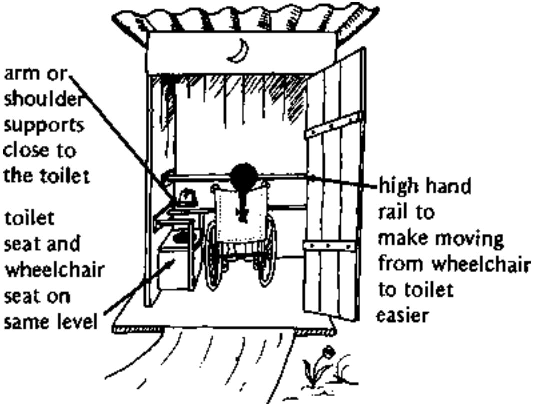


Some children, like this girl with cerebral palsy, need to sit. This potty seat was adapted from a child's wood chair.

- **Latrines can also be adapted**



Figure



Figure

2-seater latrine with child-sized hole and step

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.**

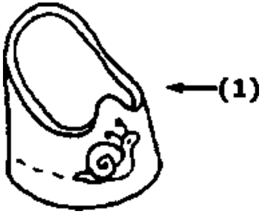
CP

simple pot

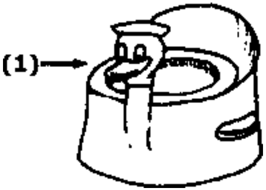
Figure

more complex pots sold in some countries

These give good back support. (1)



Figure



Figure

‘Baby Relax Toilette’ with removable pot - gives good back and side support.

Figure

For the child severely disabled with cerebral palsy, the pot can be placed between mother’s knees. This provides good back support. Mother

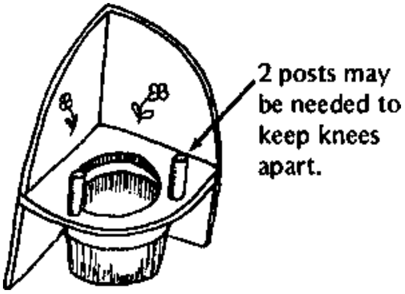
Later it may be possible to put the child on a corner seat like this - which also holds arms and

A cardboard box can also make a good sitting frame.

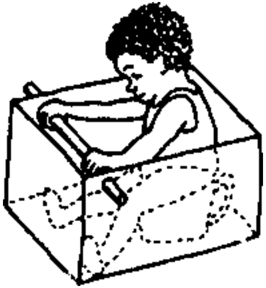
holds his shoulders forward, his hips bent and his knees separated.

Figure

shoulders forward and helps keep hips bent.



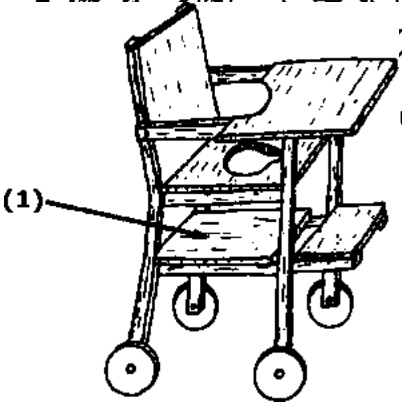
bucket



Figure

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.

Figure

Or leave the space under the seat open, so that the whole chair can be rolled over a toilet.

Put a shelf for the pot.

Figure

shelf for pot (1)

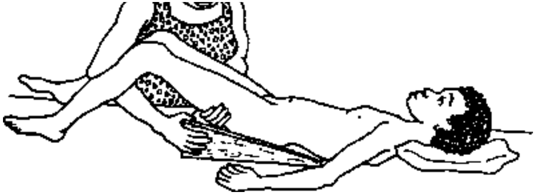
Figure

For the child who cannot sit up, you might make a wedge-shaped toilet box like this.

Figure

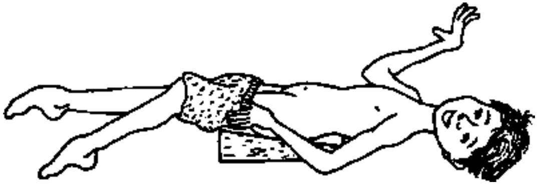
An old plastic bucket can be cut at the same angle as the bedpan so that it fits snugly under the hole.

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.



It works as a ‘bedpan’,

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.



Figure

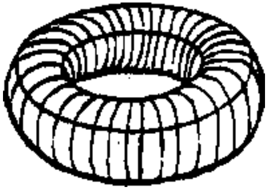
The seat can be made to fit over a bucket, over a floor-hole latrine, or over a standard toilet or on a wood or metal frame over a toilet seat.

Figure

Tire potty seat - soft, safe, washable*

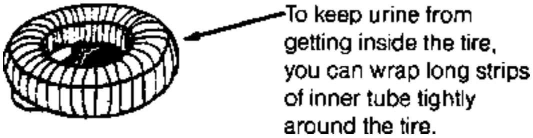
*** Ideas from India-UPKARAN manual.**

Tire can be used alone,



Figure

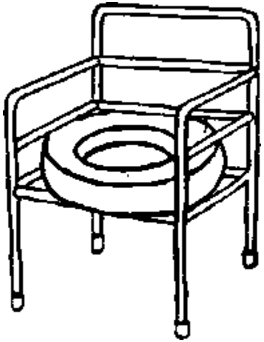
or over a 'hole-in-the-floor' toilet,



To keep urine from getting inside the tire, you can wrap long strips of inner tube tightly around the tire.

Figure

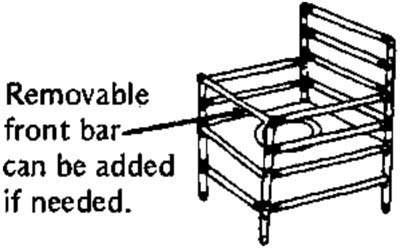
or on metal frame over a toilet seat.



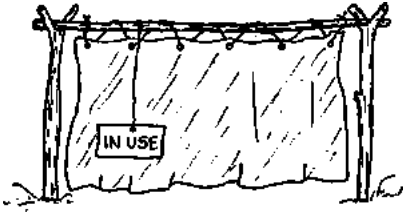
Figure

Try to pick size of tires to match the size of the child. For small children, scooter or very small car tires may work well.

Cane or rattan toilet seat with climb up bars*

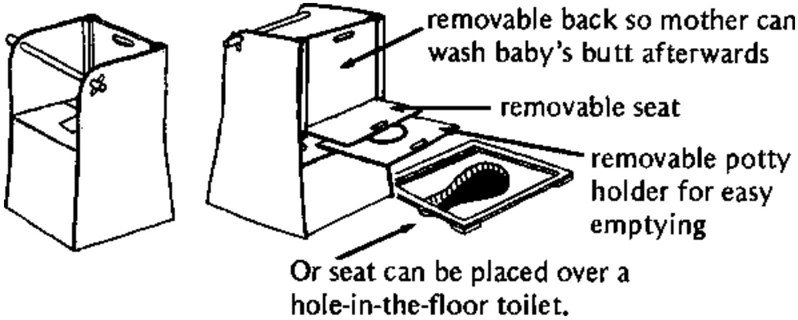


Figure



Figure

Enclosed wood or plywood toilet*



Figure

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.**

*** Ideas from India - UPKARAN manual.**

Chapter 39: Bathing (includes Care of the Teeth and Gums)

CP

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.

For the baby or small child, some kind of a tub may be a big help.

Figure

A rectangular tub of the size you need can be made out of mud or mud bricks (or dried bricks) and covered with a

Figure

CP This is a good way to hold the child who stiffens and bends backward, or throws open her arms when you pick her up.

thin layer of cement.

A mother bathes her child in a cement wash tub. (PROJIMO)

A baby that tends to stiffen backward can sometimes be held like this for bathing.

Figure

(CP) Gently spread the child's legs as wide as possible to clean between them. Also, lift arms high above the head. In this way, **bathing can be combined with range-of-motion exercises** (see Chapter 42).

Figure

IMPORTANT: Talk or sing to the baby as you bathe her. Tell her each thing you do, and the name

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.**

As the child grows, make every effort to help her take part in bathing herself. Help her do more and more until she can bathe herself without help, if possible.

Our goal in bathing is SELF-CARE, even for the child who is fairly severely disabled or *retarded.*

CP

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.

Figure

CAUTION: Be sure water is clean and does not spread disease.

2 old car tires (or inner tubes) tied together

Figure

a bath seat made from half a plastic bucket or laundry basket on a tube frame

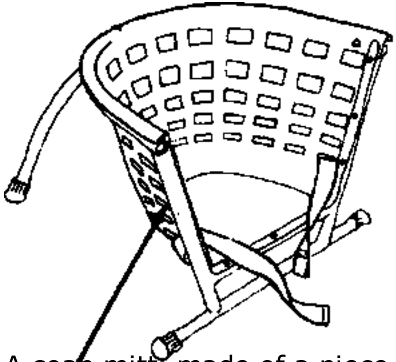
Note: Anything that keeps the hips bent up like this will help keep a child with ***spasticlty*** from stiffening and bending backward.

a stool with a seat woven from strips of car tire inner tube

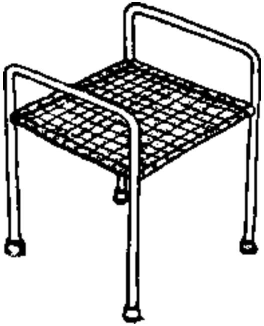
Especially for the child who does not have good ***bowel*** or urine control, it is very important to carefully clean her ***butt*** and between her legs. An inner tube on poles, like this, holds her in a good position for washing.

Figure

a washing platform of wooden slats for the child who washes (or is washed) lying down

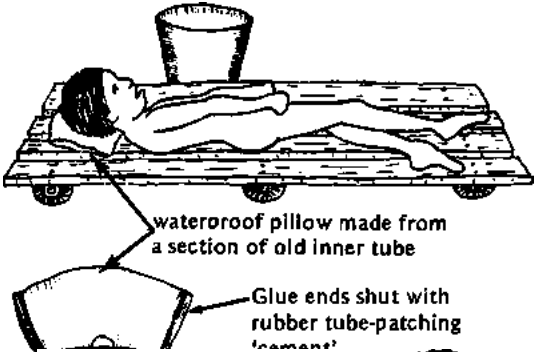


Figure



Figure

From the UPKARAN Manual.



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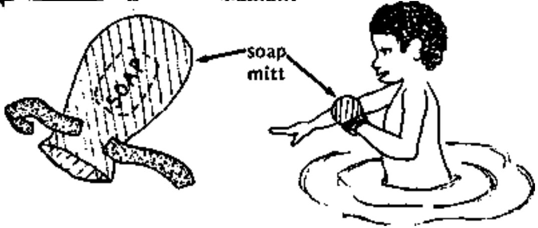


Figure

A soap mitt, made of a piece of towel and a tie string (or ***Velcro*** straps), lets the child who has difficulty grasping use both the washcloth and soap more easily.

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.

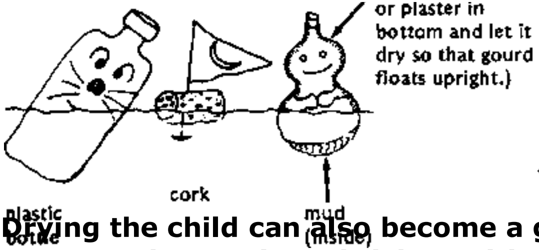
To help the child learn how to bathe herself, let her first wash her toys and dolls. Show her how and encourage her to copy you.

For a child who is afraid of the water, letting her bathe a doll or toy first may calm her fears.

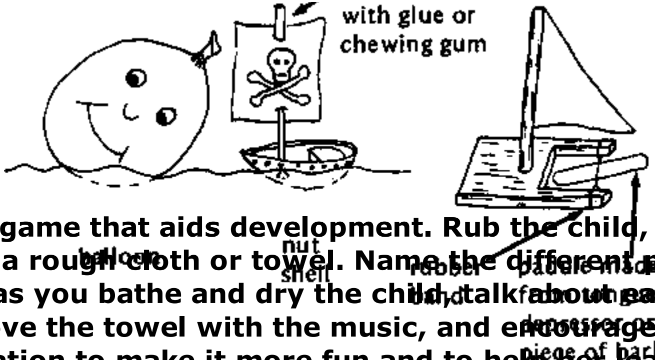
Toys that float in the water make bathing more fun. Use corks, bits of wood, or plastic bottles with lids on them. Making little boats with sails or 'paddle wheels' makes it more fun and helps the child learn to use her hands better. The child with weak lips or who drools can play by blowing the boat across the water.

Figure

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.



Figure



Figure

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.**

CP

- **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:

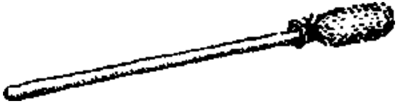
1. **Avoid foods and drinks with lots of sugar - especially between meals.**

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.**

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.

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.

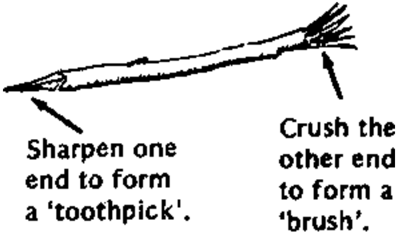


Figure

Toothpaste is not necessary. Instead you can use salt, salt mixed with baking soda, or a burned and powdered piece of bread, chapati, or tortilla, or just water.

Clean all surfaces of the teeth well, and also rub or brush the gums.

Or use a stick from a Neme tree or other non-poisonous plant.



Figure

RIGHT

This is a good position to clean the child's teeth and gums. Be sure the head bends down.

WRONG

If his head bends up, he will be more likely to choke or gag.

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.

Figure

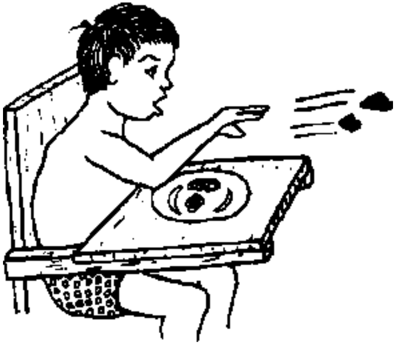
***REMEMBER:* Brushing the gums is just as important as brushing the teeth!**

For more information, see *Where There Is No Dentist,* Chapter 5, "Taking Care of Teeth and Gums".

Chapter 40: Ways to Improve Learning and Behavior

"I still feed Ral 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."

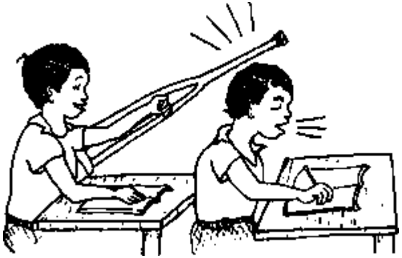


Figure

"Erica 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."

Figure

“Jorge 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!”



Figure

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 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.

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.

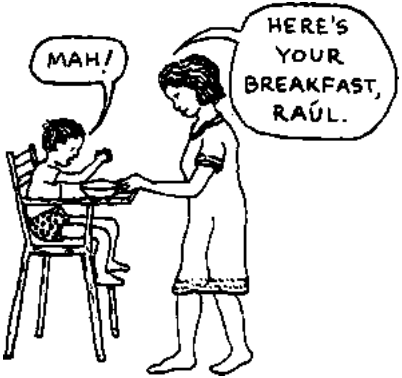
In this chapter we explore ways to do this, using a ‘behavioral approach’ which you can divide into 5 steps:

1. **Carefully observe the circumstances of your child’s unacceptable behavior.**
2. **Try to understand why your child behaves as he does.**
3. **Set a reasonable goal for improvement based on his immediate needs and his developmental level.**
4. **Plan to work toward the goal in small steps, always rewarding ‘good’ behavior and making sure ‘bad’ behavior brings no pleasure, attention, or reward.**
5. **After the child’s behavior has improved, gradually move toward a more natural (less planned) way of relating to him.**

A BEHAVIORAL APPROACH TO LEARNING AND IMPROVED BEHAVIOR

Step 1. 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, Ral’s mother might write these notes:



Figure

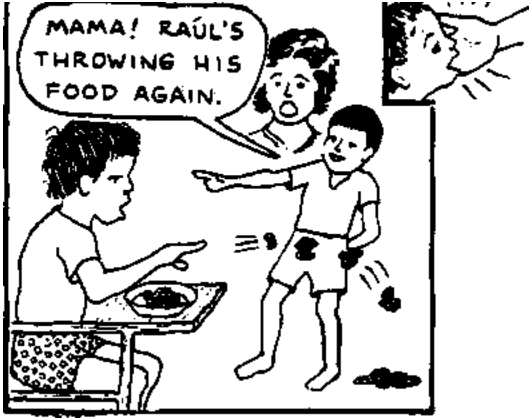
Figure

Figure

“I put him in his chair, and gave him food.”

“Then I got the older children ready for school.”

“He kept calling to me, bu was busy and told him to keep quiet.”



Figure

Figure

Figure

"Ral 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 with his toys."

Step 2. 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' his unacceptable behavior?**
- **Is his behavior partly due to confused or unclear messages from you or other persons?**

- **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 Ral began to throw food, his mother started to find some answers:

- **“Ral throws food most often when I leave him alone with it - especially when I am busy with the other children.”**

- **“My own messages to Ral 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, Ral gets a lot of satisfaction.**

POSSIBLE EXPLANATION FOR RAL’S FOOD THROWING

TRIGGERS	WHAT HE LOSES BY THROWING FOOD	WHAT HE GETS
• Ral 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

	 **Figure**	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.

Step 3. Set a goal for improvement of the child’s behavior.

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 Ral, the goal might be ‘to learn to feed himself quietly’ (not simply ‘to get him to stop throwing his food’).

Be sure that goals are possible for the child at his developmental level.

Step 4. Plan a way to help the child improve his behavior.

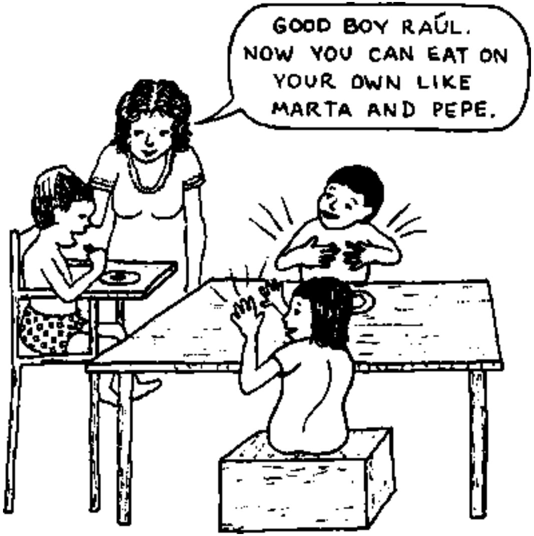
Consistently reward ‘good behavior’. Each time the child behaves as you want, immediately show your appreciation. Rewards can be words of praise, a hug, a special privilege (perhaps the chance to play with a favorite toy). Or give the child a bit of favorite food. However, food rewards should mostly be used only for very thin children or if nothing else works. Avoid giving food as rewards to fat children.

As much as possible, ignore rather than punish ‘bad’ behavior. 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.

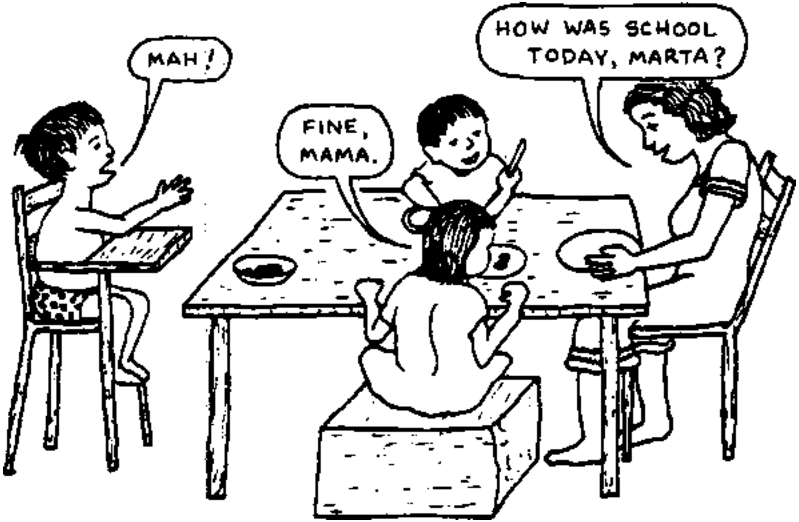
For example, whenever Ral eats by himself, without throwing his food, the whole family can applaud and praise him.



Ral 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, Ral," or, "Once more and I'll have to take your food away because I'm tired of having to clean up the mess." (Make this a result, not a punishment.) Always do what

you say you will do.



He quickly learns that throwing his food now brings no reward.

ADDITIONAL GUIDELINES:

- **Be consistent in 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 Ral 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**

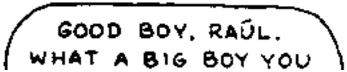
demands, but rather be consistent with her approach. Only if she is consistent will he learn that he gets more of what he wants with ‘good’ behavior than with ‘bad’.

- **Move towards the goal 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.**

For example, it would be too much to expect Ral 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 Ral’s mother to give him 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 Ral eats, but to keep talking with him and praising him when he does well.



Figure

Figure

In this way, Ral will learn that eating by himself does not mean being left alone, but gets more attention from his mother than does throwing food.

Step 5. 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.

Figure

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.

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 34, “Child Development and Developmental Delay.”)

Consider Erica, the girl who has *tantrums* (crying and screaming fits) whenever her mother puts her down. Erica 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 **Erica 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 Erica will begin to learn that she gets more of what she wants through good behavior than through tantrums.

Now suppose that **Erica 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 Erica sit at the river’s edge and pretend to help her mother wash clothes. This way Erica 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.

Figure

Figure

Note: At this level, Erica 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.

> *** 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.**

A behavioral approach can often help children who are mentally retarded or developmentally delayed, such as Ral and Erica, to relate to other persons better and to learn basic skills more quickly.

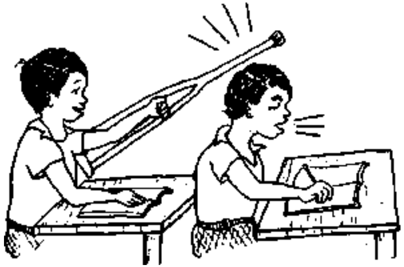
Giving lots of attention, encouragement, and praise when he makes an effort is one of the best ways to help a child learn new skills. Photo by Sonia Iskov from Special Education for Mentally Handicapped Pupils.

The 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 Jorge, to behave better.

THE STORY OF JORGE

Jorge 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. Jorge has caused so much trouble in the classroom that his teacher recently told his grandmother he will throw Jorge 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 Jorge’s behavior worse. As his grandmother says, “He loves to make people angry at him.”



Figure

Not long ago, Jorge’s grandmother took him to the village rehabilitation center to ask for advice. A village worker helped her to observe both Jorge’s and her own behavior more closely to better understand why Jorge acts the way he

At home, grandma began to look for things Jorge 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.

Figure

At school, the teacher discussed with the other children ways to include Jorge in their games. When they all played football (soccer), they let him be ‘goalie’. To everyone’s surprise, Jorge was an excellent goalie. With his crutches he could reach farther and hit the ball farther than anyone else. Soon all the children wanted Jorge to play on ‘their team’. At first Jorge started a does. She realized:

- When Jorge is quiet and well-behaved (which is not often), everyone ignores or forgets him.
- As a result, Jorge feels unwanted, unloved, and useless. Starved for emotional human contact, he gets it by making people angry with him.
- Jorge'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, Jorge 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 schoolchildren, the rehabilitation team, and Jorge himself - helped figure out ways that would let the boy see that 'good' behavior is better than 'bad' behavior.

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.

Figure

In the village rehabilitation center, the village worker invited Jorge to help make educational toys for young and disabled children. He helped Jorge get started and praised him for each toy Jorge completed. Soon Jorge 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.

Figure

Time Out’ or ‘non-reward’ instead of punishment

The story of the way family and friends used the ‘behavior approach’ to help Jorge 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.

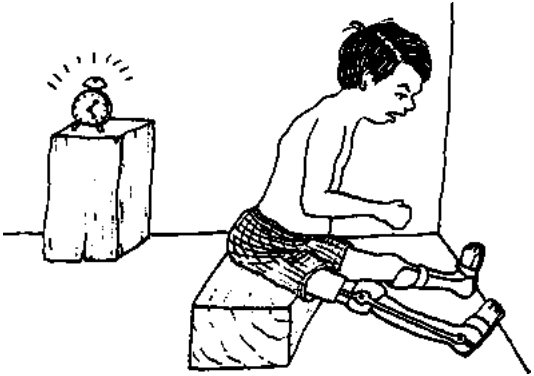
In general, the best way to make ‘bad’ behavior seem boring to the child and not worth the trouble is to give no rewarding response. At the same time, make sure to reward ‘good’ behavior. This means everything satisfying stops as a result of ‘bad’ behavior (instead of the usual situation where everything satisfying starts).

For example, when Ral 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 Jorge’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 Jorge 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.



Figure

In this way Jorge 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.

CAUTION: **For a child who is younger than 5 years old or severely retarded, do not extend time out to more than 15 minutes, checking frequently with the child to see if he is ready to behave acceptably.**

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 34 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.)

Figure

Figure

- **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.)

Figure

- **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.

Figure

Child: Celia
Age: 4

Figure

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	• plays only a moment with toys-then throws them • says ‘pee-pee’, then wets her panties	• kicks people when she gets upset • carries around a baby bottle all the time, and screams when it is taken away

 **Figure** • can feed herself with her fingers • can put 3 rings on a peg  **Figure** • undresses herself • enjoys rough play • enjoys being bathed • says 6 words: mama, dada, bottle, sweets, pee-pee and NO!	 **Figure** • **will not sit still** for a minute - except for food	• spits her food at others  **Figure**

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 Celia’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 Celia’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.

Figure

However, certain things seem to be stopping Celia from developing her skills more. Not being able to sit still 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 Celia screams. Her mother fills the bottle with sweet drinks (which have already begun to rot Celia’s teeth). The biggest problem is that by always holding her bottle, Celia’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.

Figure

For these reasons, Celia’s mother decided that the ‘key needs’, which need to be solved in order to advance in other areas, are:

- **helping Celia learn to sit quietly and give her attention to something**
- **helping Celia grow out of her need to always hold her bottle**

The health worker discussed with Celia’s mother what she might do. To help Celia learn to sit quietly and pay more attention to things, her mother decided to start with the times when Celia was already willing to sit fairly quietly - which was mealtime and bathtime. For example:

After giving Celia 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.

Figure

Figure

To make a paddle wheel boat.

Celia'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 Celia screamed and kicked. But her mother did her best not to give Celia any attention when she acted that way. As soon as Celia was quiet, however, she would give her a tasty drink from a glass, or some other reward.

Sometimes Celia 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.

Figure

After Celia 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 Celia develop other skills: dressing, eating, and talking. To increase her language skills, together they looked at picture books and listened to songs.

Figure

As a result of her family’s efforts, Celia 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 Celia’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 36; Dressing, Chapter 37; and Toilet Training, Chapter 38. We suggest you also read again the chapter on child development, Chapter 34, 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

Tantrums

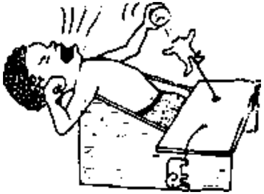
'Tantrums' are fits of crying, screaming, and angry or destructive behavior. The child may try to break, throw, kick, bite, or in other ways damage anything or anyone within reach - sometimes including himself.

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. Erica, is one example. Here is another:

Kwame has been left to play by himself. He tries to get Mama to come give him attention.

So Kwame has a tantrum.



Figure

Afraid he may hurt himself, Mama comes running to the rescue.

Now Kwame has her full attention.

Figure

Figure

REFUSING ATTENTION HERE

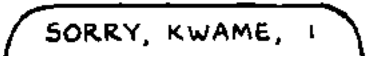
AND GIVING IT HERE→

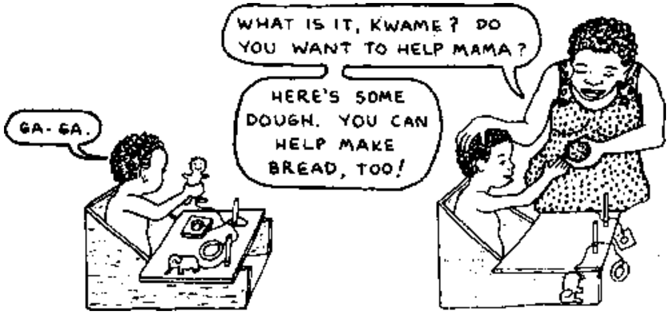
ENCOURAGES 'BAD' BEHAVIOR

In this way children discover that tantrums get them what they want. To help a child have 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 Kwame's mother learned to do this:

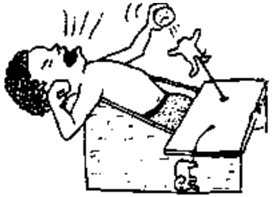
When Kwame acts nicely:

But when he has a tantrum:





Figure



Figure

Figure

GIVING ATTENTION HERE

AND REFUSING IT HERE→

REINFORCES 'GOOD' BEHAVIOR

Thus, by rewarding Kwame's good behavior and by refusing to give attention to his demands when he does have tantrums, Kwame'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!

Figure

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.

Figure

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.

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.

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.

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 when 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

Figure

"Joel 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's just alone."

Joel 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

Figure

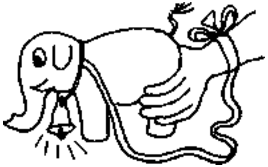
"My 5-year-old daughter, Judy, is blind and somewhat retarded. She has a habit of poking her fingers deep into her eyes. As a result, her eyes often get infected."

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.)**



Figure

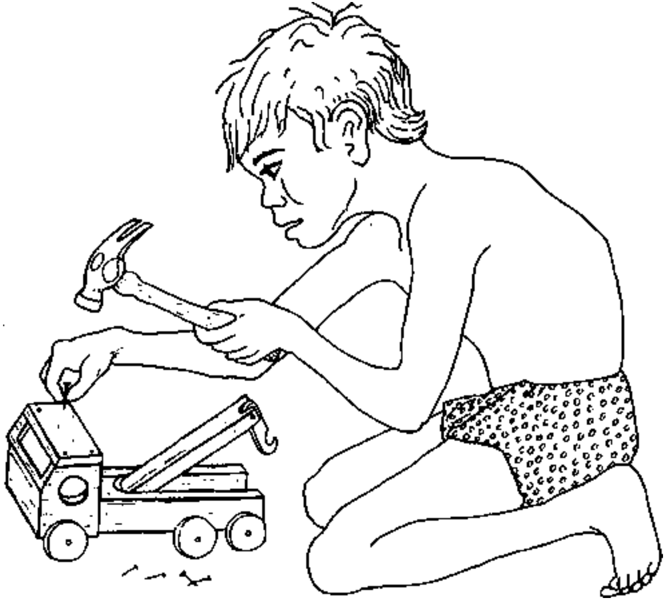
- **giving her more attention and praise when she does not rub her eyes than when she does.**

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?

Chapter 41: 'Learning Disabilities' in Children with Normal Intelligence

Some children, whose minds in most ways seem quick and normal, have difficulty learning or remembering certain things.

For example, a child may have great difficulty learning to read, often mixing up certain words, letters or numbers. Or he may have trouble remembering names of persons, things or places. These 'blocks' to learning may happen in a child who is as intelligent, or even more intelligent, than most children the same age.



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.

In developed countries at least one child in 30 is thought to have a learning *disability*. In poor countries nobody knows how many. Any child who in the first years of life seems to

develop abilities and understanding about as quickly as other young children, yet at a certain age begins to show difficulty learning or remembering certain things, may have this kind of 'special learning disability' (or call it what you like). Often these children are unusually active, have a hard time sitting still, or may develop certain *behavior* problems.

WHAT TO DO

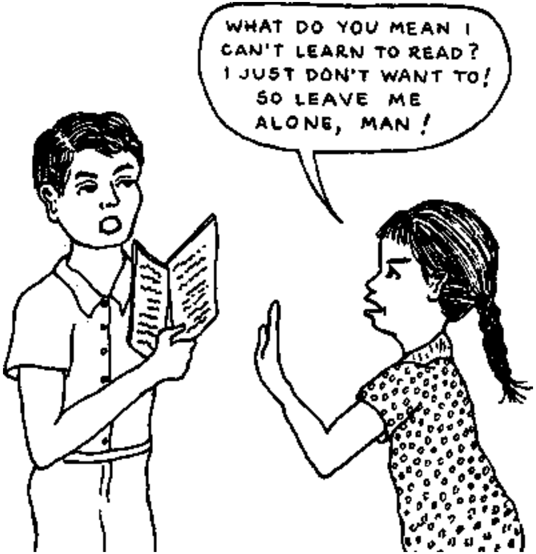
- **These children (even more than most) have a great need for love, understanding, and appreciation of the things they do well.**

- **It is very important not to treat these children as stupid or 'retarded'. Praise the child and try to help her develop in areas where she shows interest or ability.**

- **Often the best way to help a child learn in the area where she has special difficulty is to introduce it, little by little, through 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.

- **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 others that they have trouble learning something. Instead they hide their difficulty by pretending 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.



Figure

- **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 34.) Make study periods short and mix them with activities that the child likes. And of course, try to make learning fun.**

- **Let the child learn, and use what she learns, at her own speed. Do not hurry her. Help her to 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.

E. Exercises and Techniques

Chapter 42: 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
To maintain or increase	1. range-of-motion exercises (ROM)

joint motion	2. stretching exercises. 3. strengthening exercise with motion: exercises that work the muscles and move the joint against resistance
To maintain or increase strength	4. strengthening exercises without motion: exercises that work the muscles without moving the joint
To improve position	5. practice at holding things or doing things in good positions
To improve control	6. practice doing certain movements and actions, to improve balance or control

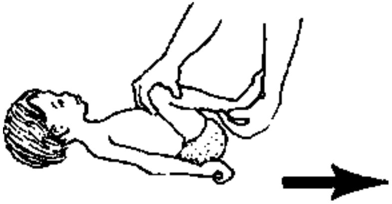
DIFFERENT KINDS OF EXERCISES AND WHEN TO USE THEM

1. Range-of-motion exercises (ROM)

Ram is 2 years old. Two weeks ago he became sick with polio and both legs became ***paralyzed**.*

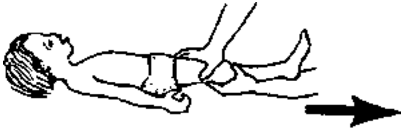
Figure

Ram needs range-of-motion exercises **to keep the full motion of his joints,** so they will not develop contractures.



Figure

At least 2 times a day, his mother slowly bends, straightens, and moves all the joints as far as they normally go.



Figure

All these are exe his knee. For oth exercises he nee

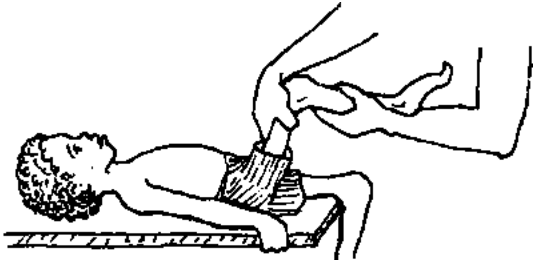
Figu

2. Stretching exercises

Lola, 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.

Lola'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.

Figure

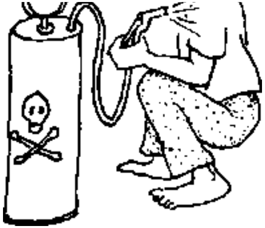


Figure

3. Strengthening exercises with motion

Chon 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,

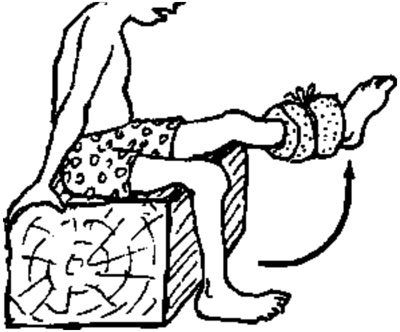
To help strengthen the weak muscles in his thighs, Chon can raise and lower his leg like this - first without added weight and later with a sandbag on his



Figure

2 months have passed, and Chon is a little stronger. But he still falls when he tries to stand.

ankle. As his leg gets stronger the weight can be increased.

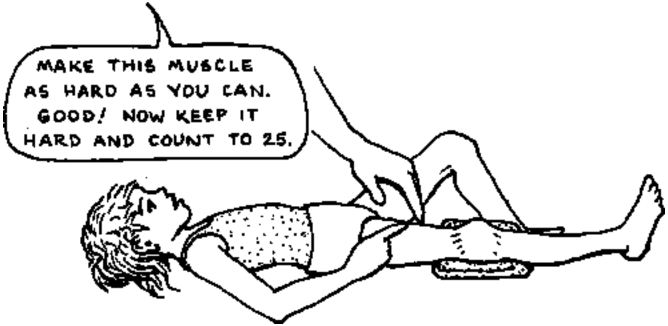


Figure

4. Strengthening exercises without motion

Clara, 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 Chon does because it hurts her knee too much.

But Clara can do exercises to strengthen her leg without moving her knee. She holds it straight and tightens the muscles in her thigh.



Figure

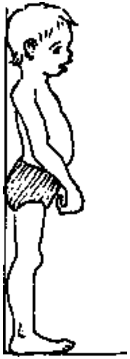
For more information on ‘exercises without motion’.

5. Exercises to improve position

Ernesto is 8 years old and has early signs of muscular dystrophy. Among other problems, he is developing a sway back.

Figure

Ask Ernesto 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.



Figure

Because swayback is often partly caused by weak stomach muscles, strengthening the stomach muscles by doing 'sit-ups' may also help. See if Ernesto 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.)

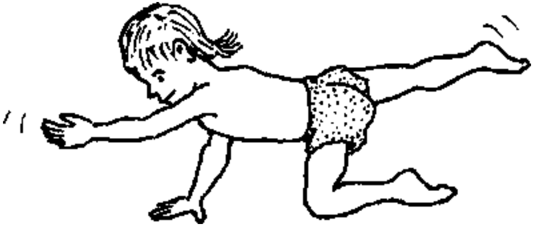
Figure

6. Exercises to improve balance and control

Celia is 3 and still cannot walk without being held up. She

Play games with her to see if she can lift one leg, and then the other.

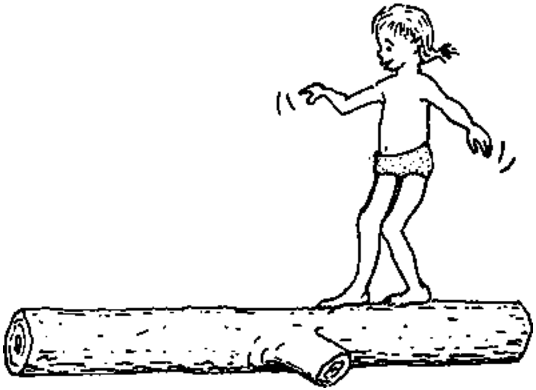
After Celia has learned to walk alone, if she still seems unsteady, walking on a log or narrow board may help her to has poor balance. Many exercises and activities might help her improve her balance and control of her body. Here are 2 ideas for different stages in her development. For other possibilities, see Chapter 35 on Early Stimulation.



Figure

This will help her shift her weight from side to side and keep her balance.

improve her balance.



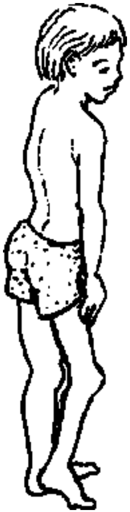
Figure

COMBINED EXERCISES

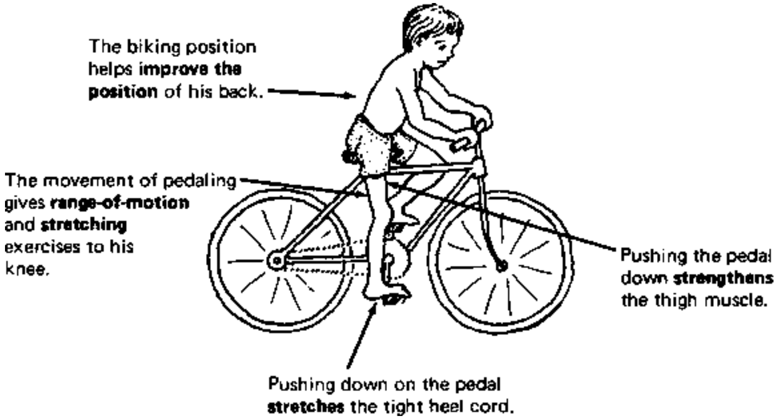
Often several kinds of exercises, involving different parts of the body, can be done through one activity - often an ordinary activity that children enjoy.

For example, Kim, who is 8 years old, had 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 Kim needs he can do by riding a bicycle.



Figure



Figure

Learning to ride **improves his balance and his control,** so that all parts of his body work smoothly together.

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.

Figure

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.

Who should do them?

Range-of-motion exercises are important for:

CP

- **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*)**

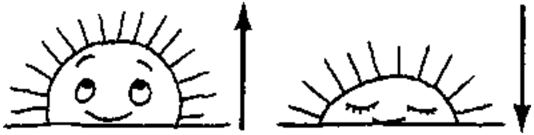
- **children with parts of their bodies paralyzed from polio, injury, or other causes, especially when there is muscle imbalance, with risk of contractures.**

- **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.



at least twice a day

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. Starting range-of-motion exercises EARLY can reduce or prevent disability.

<table>
<tr><td>
Figure</td><td colspan="2">KOFI AND MEDA</td><td>
Figure</td></tr>
<tr><td colspan="4">Kofi and Meda got meningitis on the same day. With quick, good medical treatment both survived. But both had suffered brain damage that left their bodies stiff and bent.</td></tr>
<tr><td colspan="2">From the time his fever dropped, Kofi’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</td><td colspan="2">Meda’s mother cared for her child as best she could, but no one told her about exercises.</td></tr>
</table>

possible.

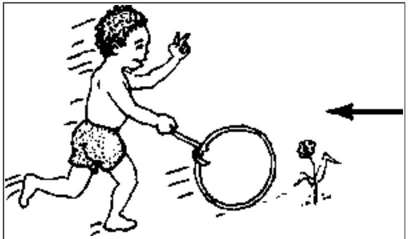
Little by little Kofi's body began to loosen up.

Meda'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 Kofi'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.

When Meda'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.



Figure

RESULTS WITH AND WITHOUT RANGE-OF-MOTION EXERCISES

Figure

It is much easier to prevent these

problems than to correct them.	 **Figure**

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?

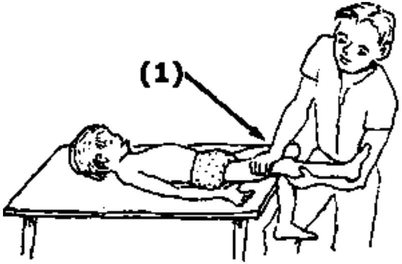
Exercise all the joints that the child does not move through normal range of motion during her daily activities. For a child who is very ill or newly paralyzed, this may mean exercising all the joints of the body. For a child with one paralyzed limb, range-of-motion exercises usually only need to be 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 straighten	than when the hip is bent	This is because some	To prove

The knee will often straighten more (and you will be stretching different muscles) when the hip is straight, (1)

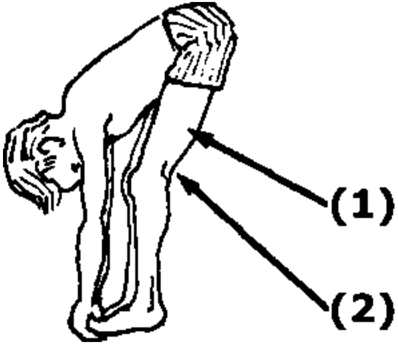


Figure

than when the hip is bent.

Figure

This is because some muscles go from the hipbone to below the knee.



Figure

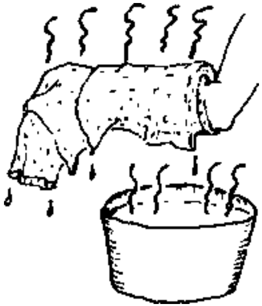
To prove this, try to touch your toes with your knees straight. You will feel the muscles (1) stretch, and the cords tighten here. (2)

In a similar way, movement in the ankle is affected by the position of the knee, and movement of the fingers by the position of the wrist.

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.

For a stiff, painful joint, apply heat for 10 or 15 minutes before doing the exercises.

Figure



Figure

Figure

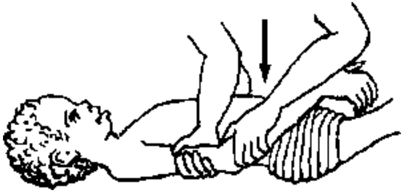
3. Move the joint SLOWLY through its complete range of motion.

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.



Figure

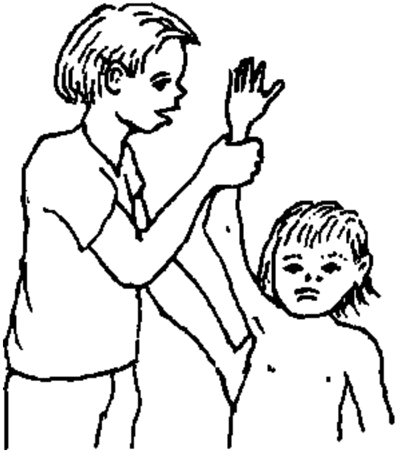
Figure

Figure

The more often you repeat this, the faster the limb will get straighter.

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).



Figure

Figure

Figure

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 or he can move the limb through its full

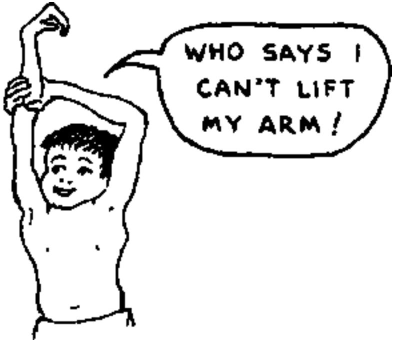
at all, either you can do it for him...

Figure

Figure

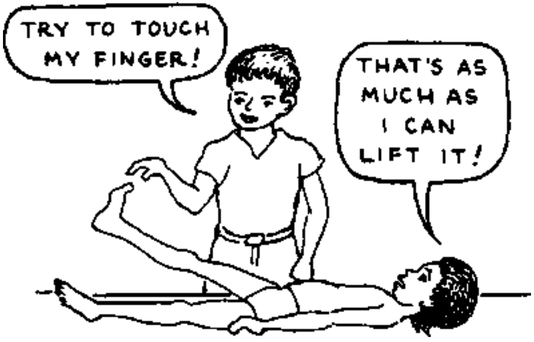
Figure

range with another part of his body.



Figure

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.



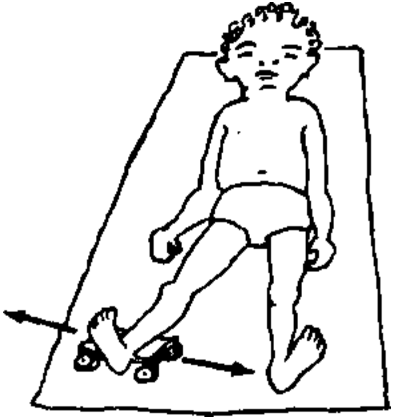
Figure

Figure

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. If he can lift the weight of his limb If he can lift the limb's 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.

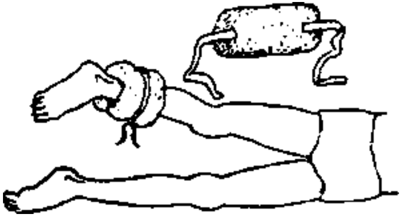


Figure

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.

Figure

weight easily, add resistance by pushing against the limb or by tying a sandbag to it. This helps strengthen the muscles for that motion.



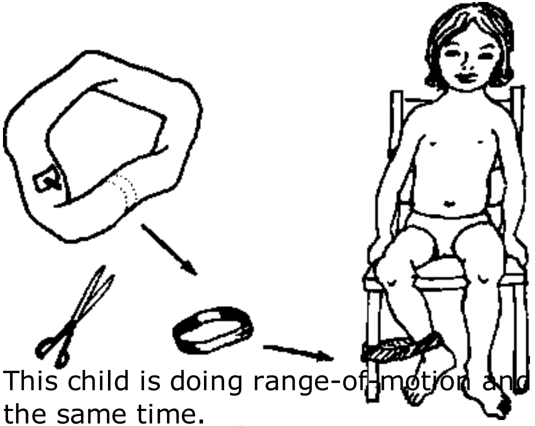
cloth bag filled with sand

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.

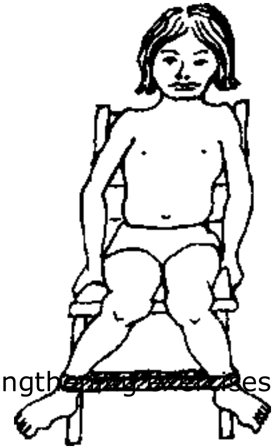
Twist the leg *in* (and the hip *out).*

Twist the leg *out* (and the hip *in).*



This child is doing range-of-motion and strengthening exercises at the same time.

Figure



Figure

COMMON SENSE *PRECAUTIONS* WHEN DOING EXERCISES

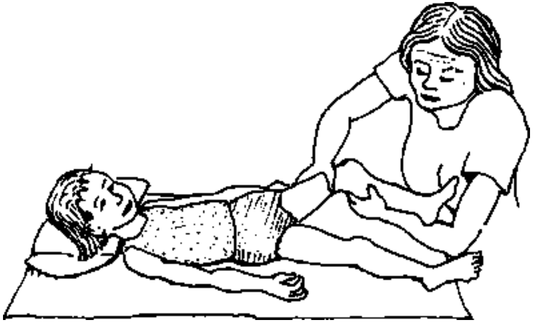
Every child's needs are different. Please do not simply do, or recommend, the same exercises for each child. First THINK about the child's problems and needs, what exercises might help her most, and what could possibly harm her. Adapt the exercises to the child's needs, and to how she responds. Here 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.

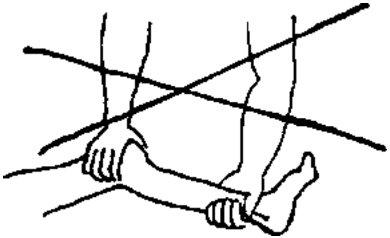
Hold the leg firmly ***just above*** the knee.

Do *not* push directly on the joint.

Do *not* pull far from the knee.



Figure



Figure

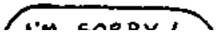
Hold the leg ***just below*** the knee and support the whole leg with your arm**.**

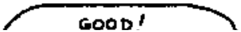
WARNING: Pulling here can dislocate the knee (or break the bone).

2. Be gentle-and move the joints SLOWLY - especially when a child has spasticity, or when joints are stiff or painful.

WARNING*:* Moving spastic joints rapidly makes them stiffer. SLOW DOWN!

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:





Figure

Figure

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.

Figure

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,

Figure

do ***not*** do ROM or stretching exercises that pull the foot up.

Figure

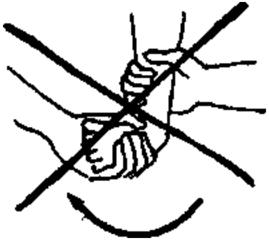
Or if a child's foot bends ***in*** more than normal, but does not bend ***out,***

Figure

do exercises to bend the foot ***out,***

Figure

but do ***not*** do exercises that bend the foot ***in.***



Figure

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.

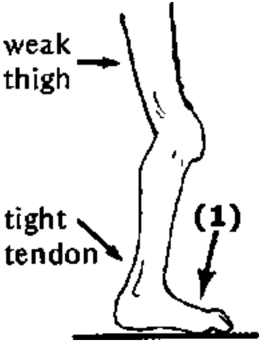
Sometimes, certain contractures or joint stiffness may actually help a child to do things better.

For example, a child with a short leg may walk better if a tight heel cord keeps his foot in a tiptoe position.

Figure

Similarly, a child with paralysis in the thigh muscles may actually walk better if a tight heel cord prevents his foot from bending up.

This foot does not bend up. The tight heel cord holds the leg back and keeps the knee from bending. (1)



Figure

Stretching exercises to bend the foot up may cause the weak knee to bend when the child tries to walk.

Figure

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!**

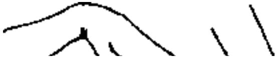
with ROM back exercise

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



For the same reason, the quadriplegic child should bending the wrist back. Tight cords make the fingers bend.

RIGHT

To keep this holding function, straighten fingers with wrist bent down,

Figure

WRONG

Do *not* stretch the fingers with the wrist bent back.

also learn to support herself on her hands with her fingers bent, not straight.

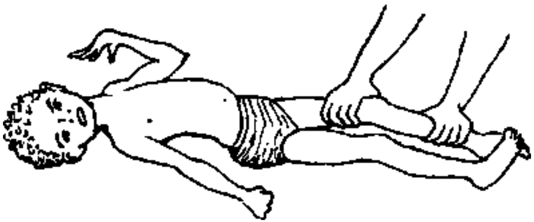
RIGHT

WRONG

7. In doing range-of-motion exercises for a stiff neck, caution is needed to make sure the neck bones do not slip and cause damage to the *spinal nerves.* This damage can cause total paralysis or even death. The danger is especially great in persons with arthritis, 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. 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.



Figure

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.

Figure

A hammock is good for positioning the child with cerebral palsy who stiffens backward.

It may also help to rotate the leg outward before trying to bend the knee.

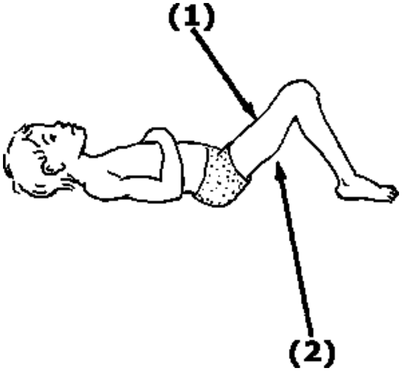
REMEMBER: Fast movements increase spasticity.

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, do exercises to strengthen the weaker muscles, not the stronger ones. This will help to prevent contractures by making the muscle balance more equal:

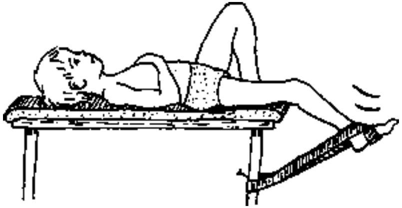
If the muscles that straighten the knee are weak, (1)



Figure

and the muscles that bend the knee are strong, (2)

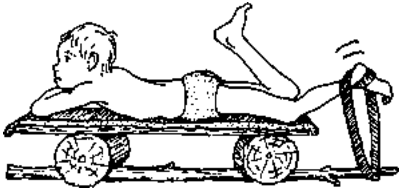
then do exercises that strengthen the weaker side.



Figure

This will make stronger the muscles that straighten the knee. It helps prevent contractures.

Do ***not*** do exercises that strengthen the stronger side.



Figure

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.

LOOK FOR WAYS TO MAKE IT FUN!

a good ROM exercise for fingers

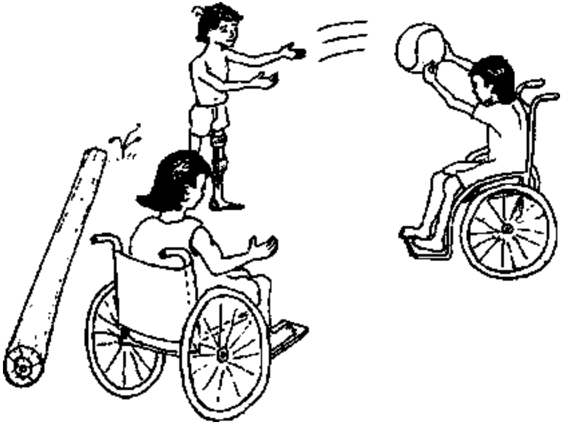
Figure

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 the muscles that straighten them.

Figure

In the picture below, children play ball to help Mara, a girl with juvenile arthritis, stretch her stiff joints and muscles.



Figure

Can you see how the 2 children on the left are helping Mara 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 one 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 Mara 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*

> *** Drawings on pages 378 to 380 are adapted from *Range-of-Motion* by Hewitt/Jaeger.**

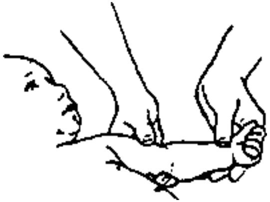
Do these exercises slowly and steadily. Never use force, as this could damage a joint.

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

Figure

SHOULDER: arm back and forwar



Figure

Move arm all the way back,
and
over

SHOULDER: rotation

Figure

With elbow bent

Figure

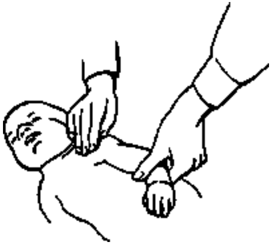
turn the arm all the way up,

strai

Figure

then all the way down.

SHOULDER: out to side



Figure

Raise arm straight out to side.

ELBOW: straighten and bend

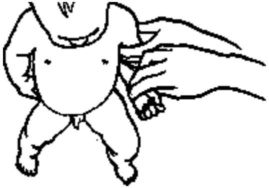
FOREARM: twist

Figure

Straighten the arm out from the side,

Figure

then bend the elbow to bring hand up to shoulder.



Figure

Holding the wrist twist the hand up,

and (gen

WRIST: up and down

WRIST: side to side

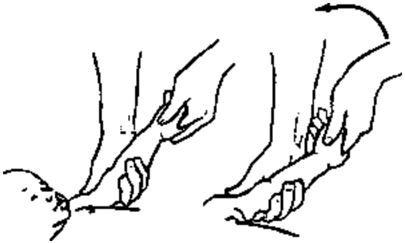
Figure

Figure

Bend wrist back,

Figure

and then forward.

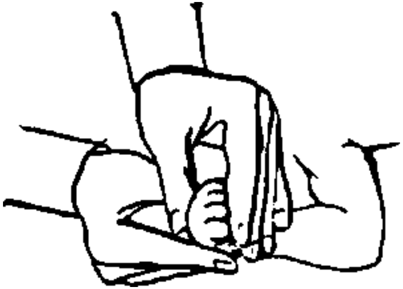


Figure

Bend to outside.

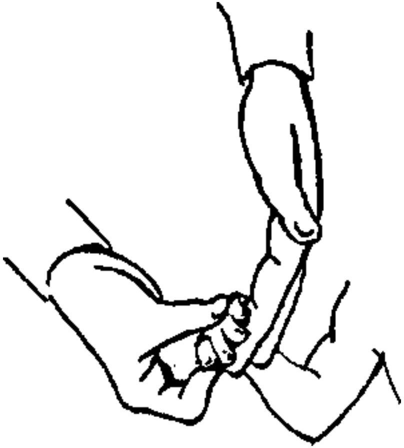
Ben
not
side.

FINGERS: close and open



Figure

Make a fist.



Figure

Straighten gently.

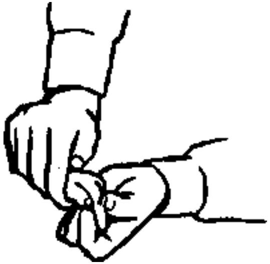
FINGERS: spread

Figure

Spread each finger one at a time.

FINGERS: straighten while bent at hand

Figure

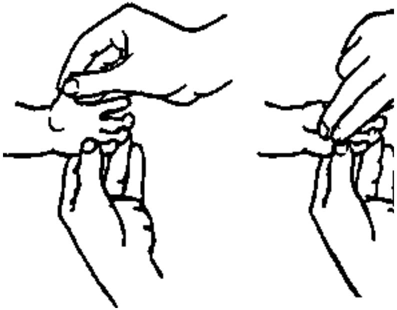


Figure

THUMB: shut and open

Figure

THUMB: for grasping



Figure

Bend thumb toward base of little fi

THUMB: up and down

down

Bend the joints of the thumb in all the way,

Figure

then open thumb all the way to the side.

Move straightened thumb down ar flat and fingers open.

Range-of-motion exercises - lower limbs

(Also see the exercise sheets)

KNEE

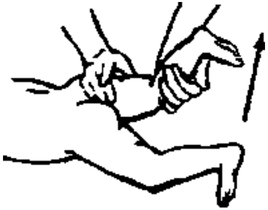
Figure

Bring heel back as far as possible,

Figure

then straighten leg as much as possible.

HIP: straighten



Figure

Be sure hip stays flat a

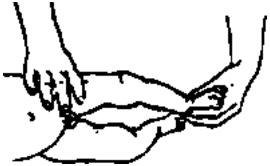
HIP: bend

HIP: spread

leg

Figure

Figure



Figure

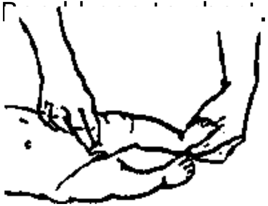
Straighten all the way.

Spread hips open as far as you can

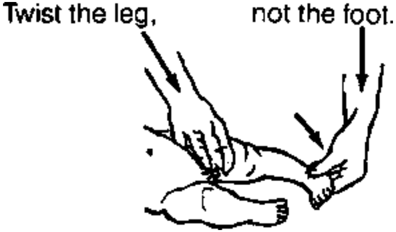
HIP: twist (rotation) - leg straight

[illegible]

HIP ROTATION: leg bent



Figure



Figure

Figure

Figure

Fig

then to outside.

With knee bent,

swing leg out,

Roll leg and foot to inside,

ANKLE AND FOOT: down and up.

Figure

IMPORTANT: To stretch a tight he

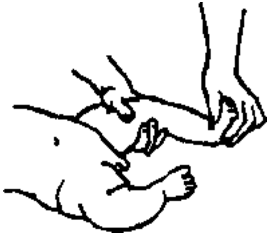
Pull heel harder than you push on foot - or you may dislocate foot upward instead of stretching the ankle cord and muscles.

Bend foot down.

Figure

Pull heel down and bend foot up.

ANKLE TWISTING: in and out



Figure

Figure

Twist in.

Figure

Twist out.

TOES: up and down

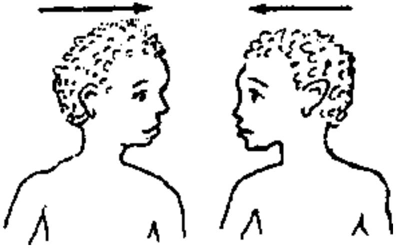
Figure

Bend toes up.

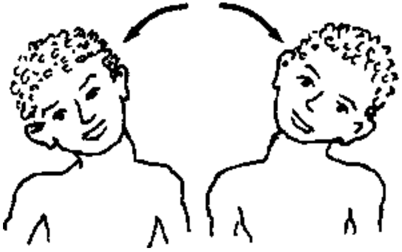
Range-of-motion exercises - neck and trunk

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.)

NECK



Figure



Figure

Figure

Figu

Turn head to left and to right,

side to side,

up and down,

and back and fo

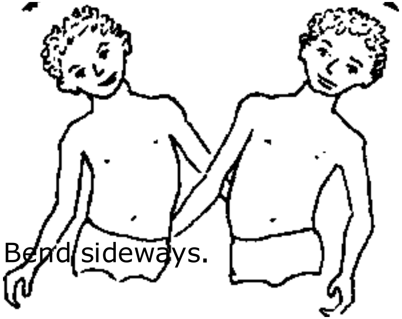
TRUNK

Figure

Bend back.

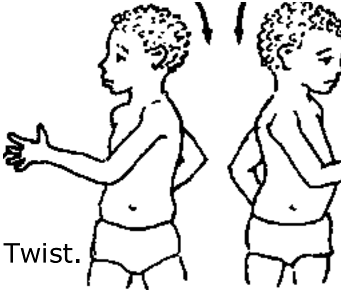
Figure

Bend forward.



Figure

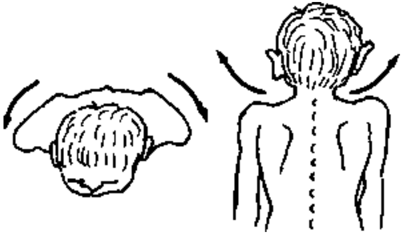
Bend sideways.



Figure

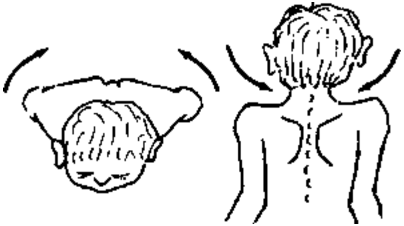
Twist.

UPPER BACK (shoulder blades):



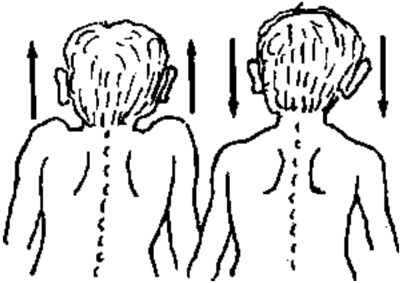
Figure

Bringing shoulders forward, pulls the shoulder blades wide apart.



Figure

Pulling shoulders back, pushes the shoulder blades close together.



Figure

Pull shoulders Push shoulders up toward ears down.

RIBS

Figure

Breathe in deeply.

Figure

Breathe out deeply. See how long you can whistle or blow.

(Blow a whistle or blow up a balloon.)

JAW

Figure

Figure

Figure

Pull jaw back,

and push forward.

Open mouth wide.

Move jaw to one side,

and then to the other side.

Figure

Figure

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 home 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.

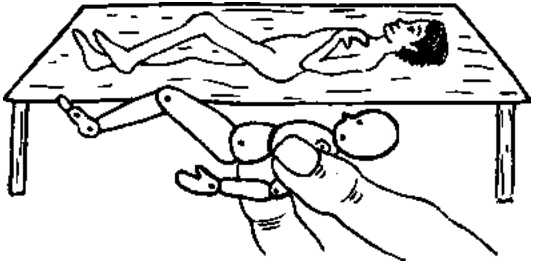
Figure

Figure

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.)

Figure



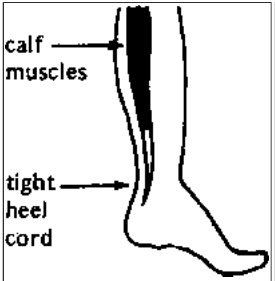
Figure

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

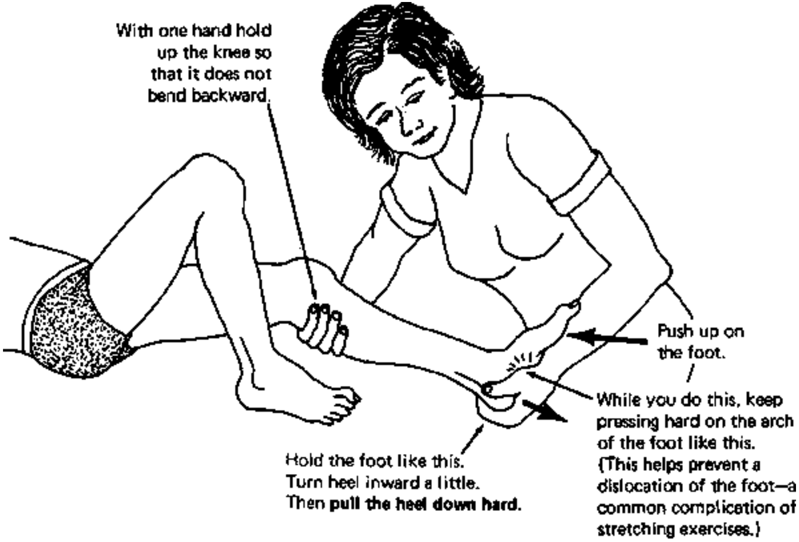
community. (See Chapters 1 and 2.)

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

EXERCISE SHEET 1

 **Figure**	**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.

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



Figure

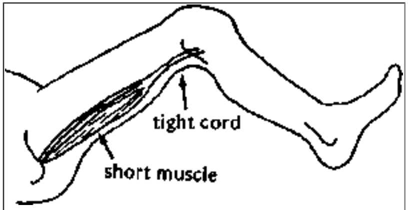
Pull down on the heel and push up on the foot, firmly and steadily while counting slowly to 25. Relax, then do it again. Repeat this exercise 10 to 20 times - in the morning, at noon, and in the evening.

WARNING: Pushing here can injure the knee of 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**	 **WRONG**

STRETCHING EXERCISE-TO STRAIGHTEN A STIFF KNEE (KNEE CONTRACTURE)

EXERCISE
SHEET
2

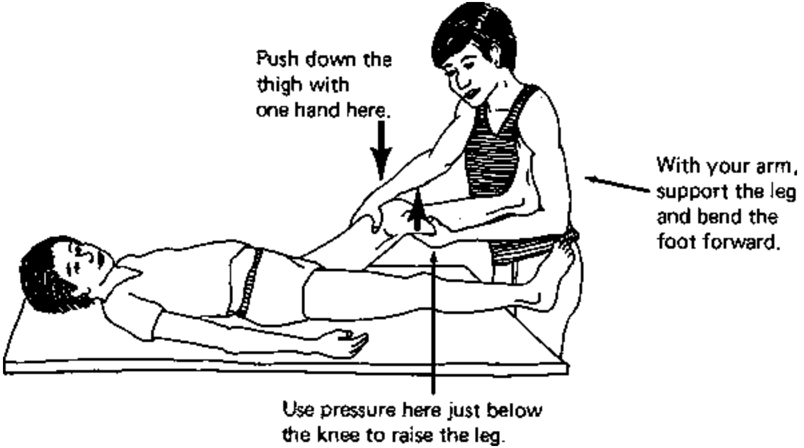
 **Figure**	**PROBLEM** The muscle and cord here are too short and tight. For this reason the knee will not straighten.

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.

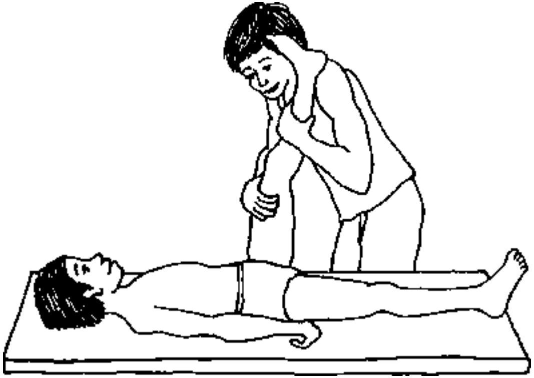
Both of you keep working to hold the knee as straight as possible while you count slowly to 25. Repeat several times. Do this exercise 3 times a day.

If the foot also has a contracture, try to hold or bend it up while you stretch the cord

behind the knee.

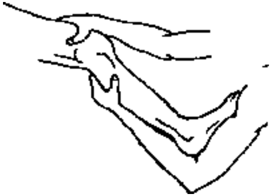
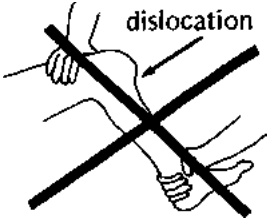


Figure



Figure

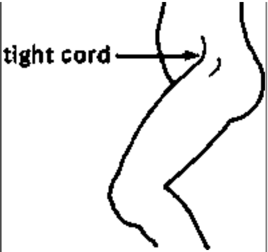
When you get the knee as straight as you can with the hip extended, gradually lift the leg higher, keeping the knee straight.

LIKE THIS	NOT LIKE THIS
 **Figure**	 **Figure**
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

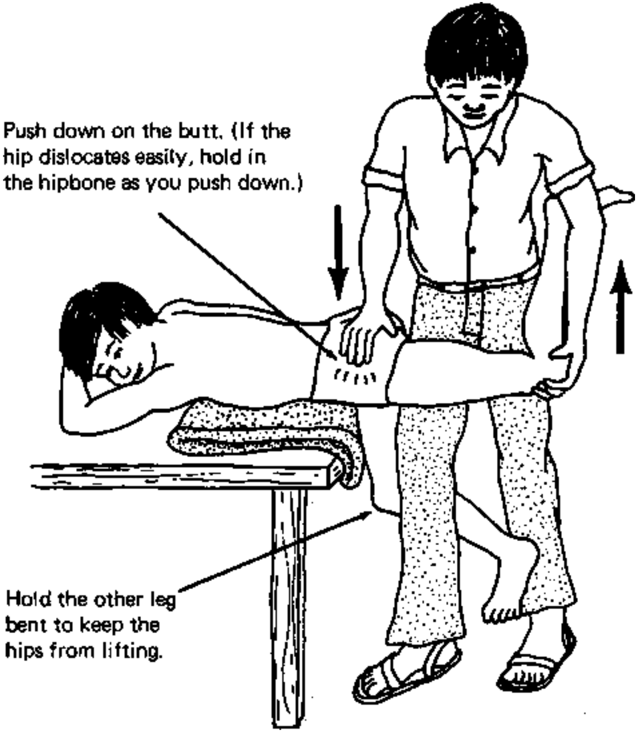
EXERCISE SHEET 3

PROBLEM The thigh is pulled forward by tight cords and cannot straighten backward.	

	 **Figure**

Rest the thigh against your thigh, and support the leg with your arm.

With firm and steady force, pull the leg up while counting slowly to 25.

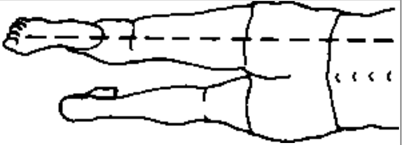
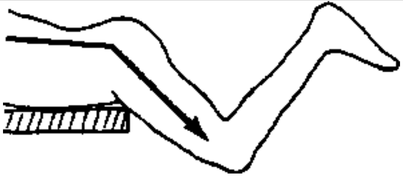
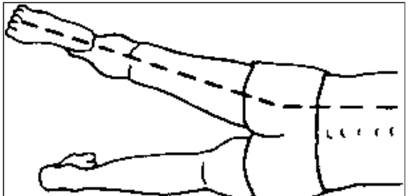


Figure

Rest the thigh against your thigh, and support the leg with your arm.

With firm and steady force, pull the leg up while counting slowly to 25.

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.	
 **Figure**	LIKE THIS	 **Figure**	LIKE THIS
 **Figure**	NOT LIKE THIS	 **Figure**	NOT LIKE THIS

EXERCISES AND POSITIONS TO HELP AVOID PRESSURE SORES AND CONTRACTURES

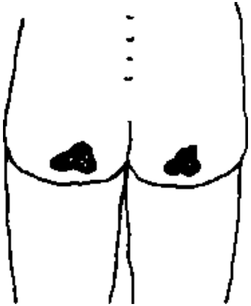
EXERCISE SHEET 4

Children who spend a lot of time lying or sitting, or have lost feeling in their butts, should NOT SPEND ALL DAY SITTING DOWN. This can cause pressure sores, contractures of the hips and knees, and back deformities.

PREVENT THIS ***PREVENT THIS***

Contractures

Hips and knees are contracted (cannot be straightened) from sitting too much. (1)

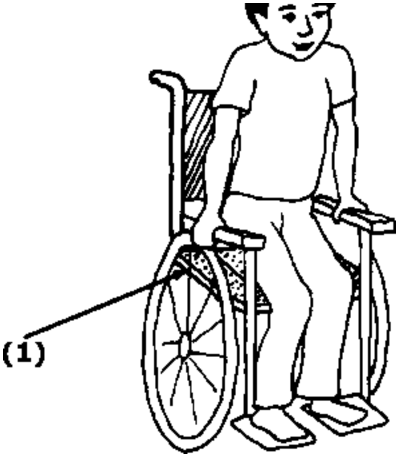


Figure

Pressure sores

When you spend time sitting in a wheelchair (or any chair) lift yourself up with your arms like this and count to 25 every 1 5 or 20 minutes.

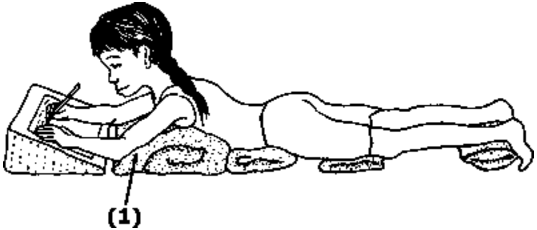
Lifting up often is especially important for people who do not have feeling in their butt, so that they do not get sores on their bottom.



Figure

Be sure to use a soft cushion. (1)

Spend a part of the day lying down with your shoulders up like this.

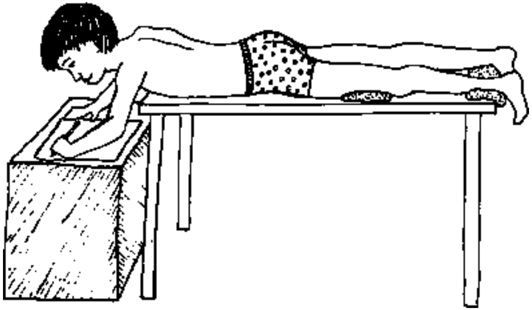


Figure

cushions or foam rubber wedges (1)

You can do schoolwork lying down. Try to

If the child cannot straighten enough to lie on the arrange things with the teacher so that you can spend part of your day lying down.



Figure

floor, he can lie on a table, and work or play with his hands at a lower level, as shown here.

BE CAREFUL: To avoid sores, it is important to put foam rubber cushions to protect the body where bones press against skin-especially if you cannot feel in parts of your body.

EXERCISE FOR A STRAIGHTER BACK

EXERCISE SHEET 5

PROBLEM

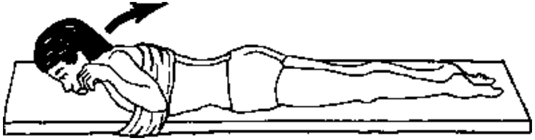
The upper back bends forward (in older persons this is a common cause of high

Lie face down and move the arms as shown. This helps keep the shoulder blades and upper back flexible.

back pain). Often the shoulders and shoulder blades are also stiff.

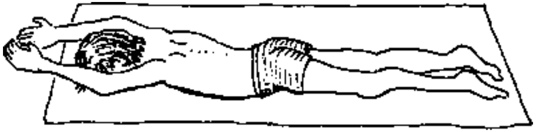
Figure

Put a strap around the upper body and bend backward as far as you can.

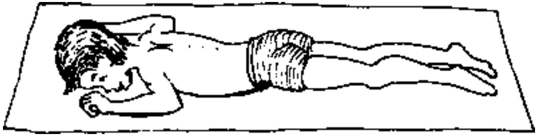


Figure

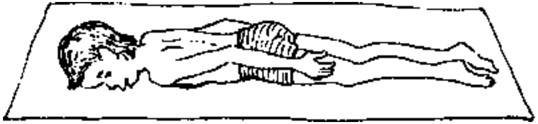
Or put pressure against the middle of the upper back and have the child try to straighten against it.



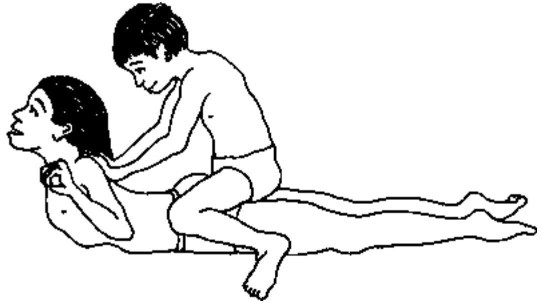
Figure



Figure

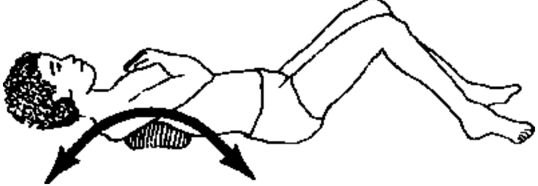


Figure



Figure

Stay in this position while you count to 25. Do the exercise 2 or 3 times a day.

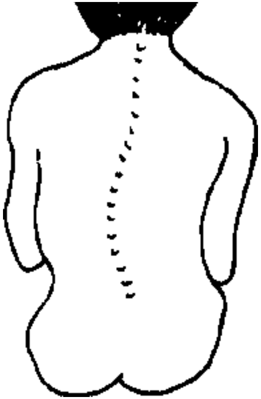


Figure

Also, for at least half an 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 your body bend backward over the roll.

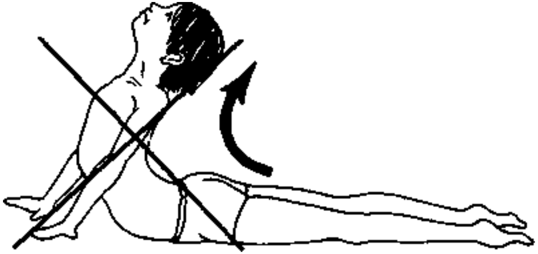
Note: Some experts believe that the exercises that bend the back up and back, as shown above, may also help keep a mild sideways curve of the spine (scoliosis) from getting worse. But the exercises will not help much if the curve is severe.

[redacted]

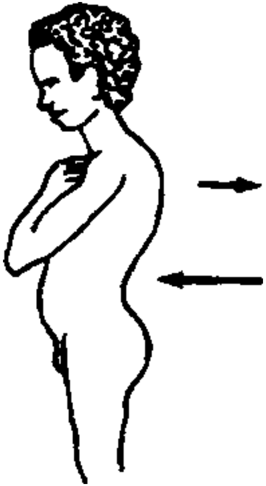


Figure

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.



NO!

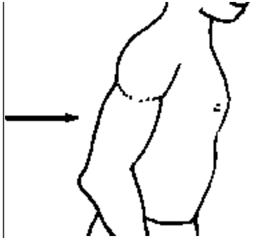
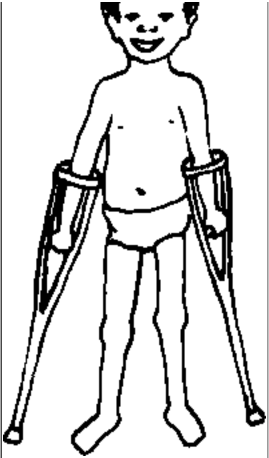


Figure

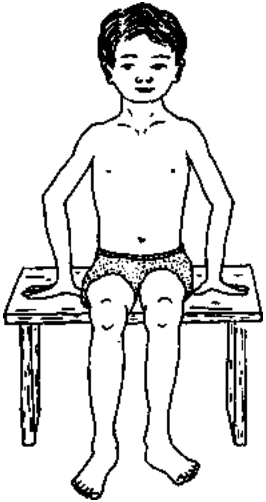
STRENGTHENING EXERCISES-TO GET ARMS READY TO WALK WITH CRUTCHES

EXERCISE SHEET 6

	**OBJECTIVE** These exercises help make your arms stronger so that you can walk with crutches.	

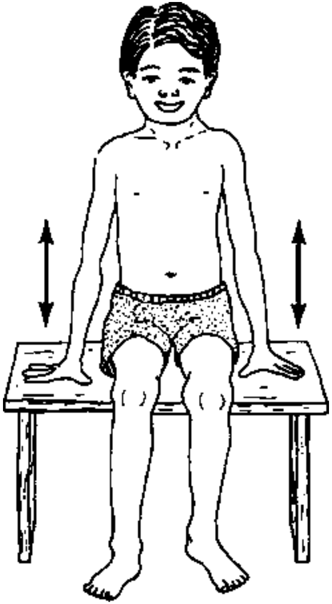
 **Figure**		 **Figure**

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.



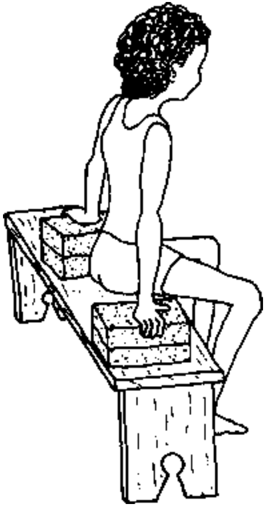
Figure

Note: If the child’s arms are too short to lift himself up on open hands, he can use his fists.



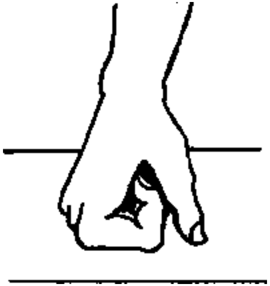
Figure

Try to lift yourself with your elbows out, like this,

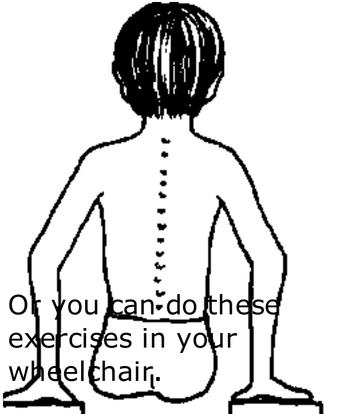


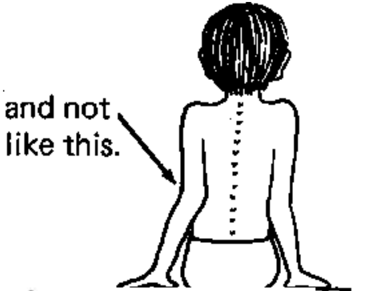
Figure

and not like this.



Figure

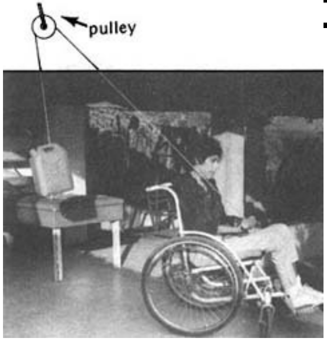




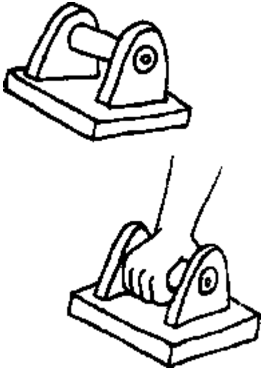
To practice for using crutches, make 'handgrips'.

Or use a sawed-off crutch.

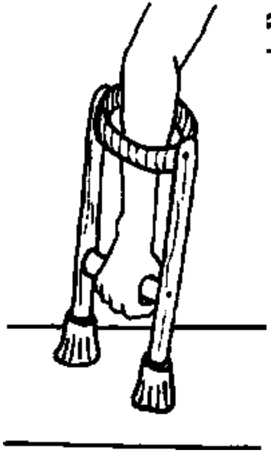
Or you can do these exercises in your wheelchair.



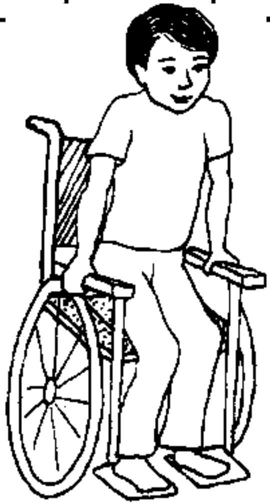
Weight lifting. Increase the weight little by little as the arms get stronger.



Figure



Figure



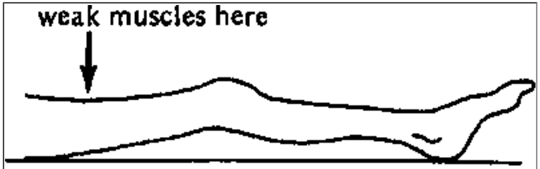
Figure

Do these exercises 3 or 4 times a day. Every day try to lift

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 EXERCISES-TO HELP YOUR CHILD HAVE STRONGER THIGHS

EXERCISE SHEET 7



Figure

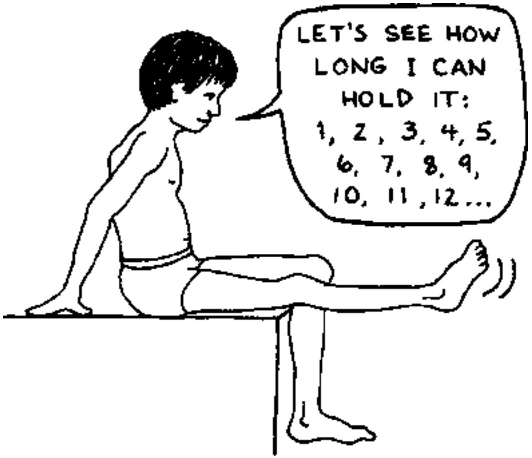
PROBLEM

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.

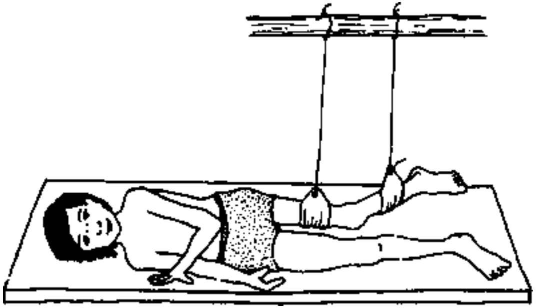
Repeat as many times as possible (until you cannot lift the leg more).

Do this exercise 2 or 3 times a day.



Figure

If the child cannot straighten her leg by herself, help her, but ask her to use all her strength too.

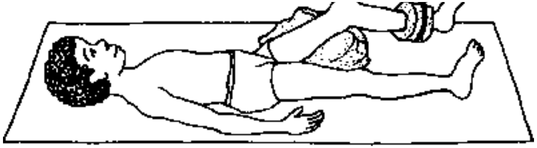


Figure

Figure

If her thigh is quite weak, have her straighten and bend her leg **lying sideways.** She may need to have the leg supported.

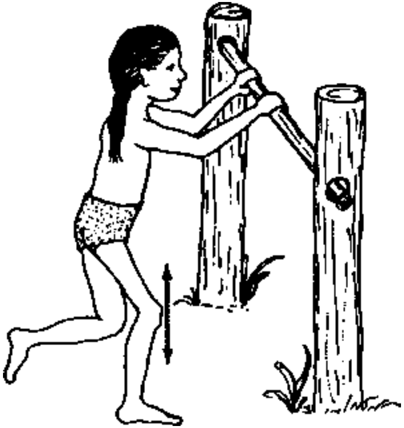
It also helps to stand on the leg, then bend as far



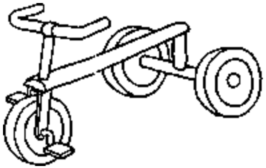
Figure

When his thigh is stronger, put a little bag of sand on his ankle so that he will use more strength to raise it.

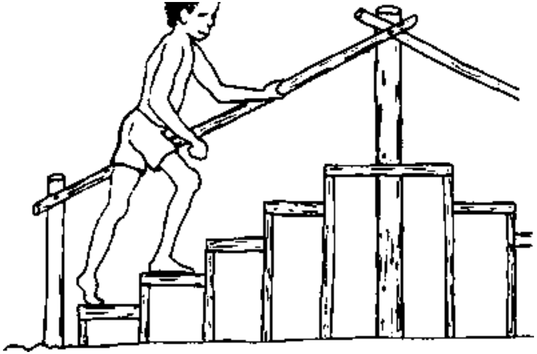
It also helps to stand on the leg, then bend as far as possible and straighten again. Repeat many times.



Figure

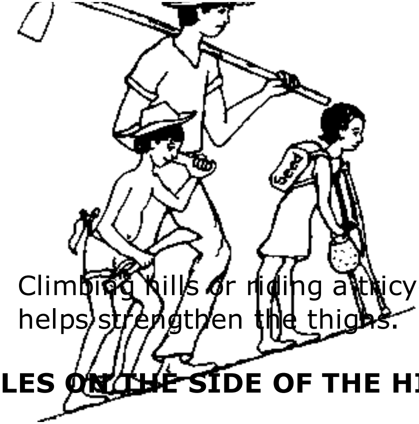


homemade tricycle



Figure

If the leg gets strong enough, practice going up and down steps. Start with low steps and slowly progress to higher ones.



Climbing hills or riding a tricycle or bicycle also helps strengthen the thighs.

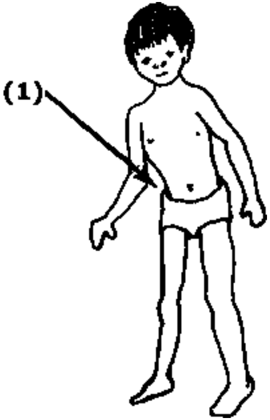
Figure

STRENGTHENING EXERCISE-FOR THE MUSCLES ON THE SIDE OF THE HIP

EXERCISE SHEET 8

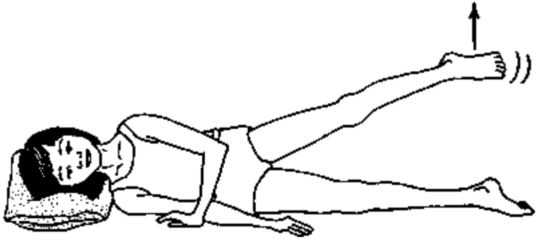
PROBLEM

weakness here causes the child to bend to one side when he walks. (1)



Figure

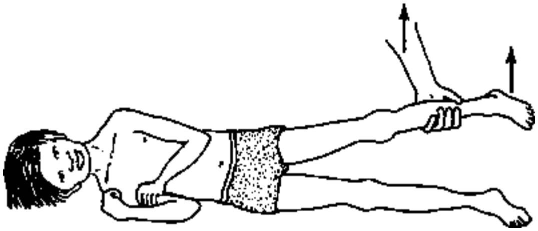
Lie on your side and raise your leg as high as you can.



Figure

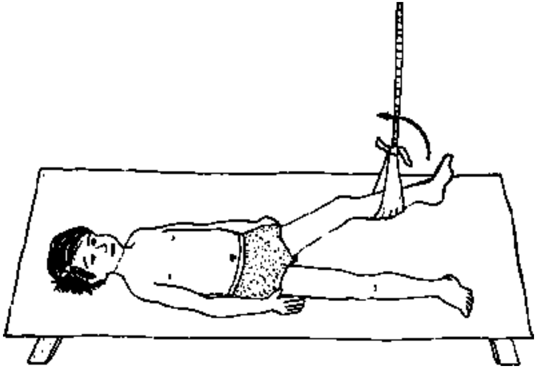
Keep your leg up until you get so tired that it falls by itself.

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.



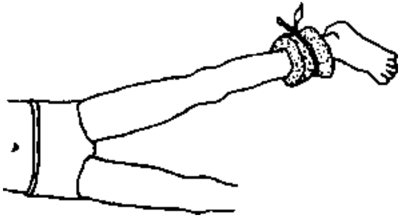
Figure

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.

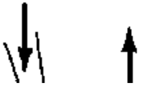


Figure

As he gets stronger, move the rop
more to the other side to make hir
work harder.

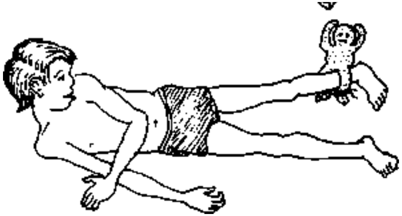


Figure



Figure

If the child can raise her leg easily, add weight with your hand, or with a little bag of sand.



Figure

Think of ways to make the exercis fun.

Repeat 3 times. Do this 3 times a day.

RANGE-OF-MOTION AND STRENGTHENING EXERCISES-FOR THE HAND AND WRIST

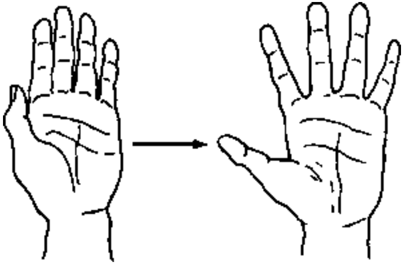
EXERCISE SHEET 9

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 have 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.

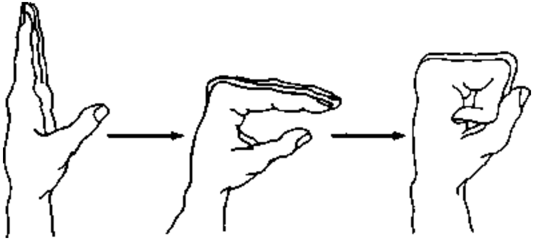
Repeat each exercise 10 to 20 times, at least 2 times every day.

1. Close and spread the fingers as much as possible.



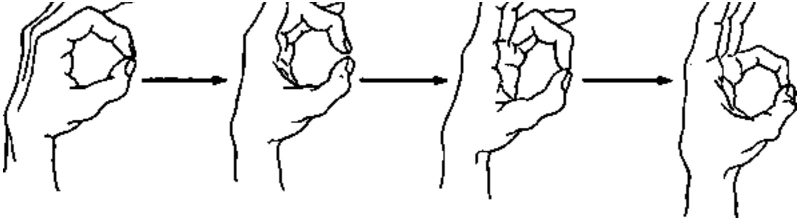
Figure

2. Bend like this. Make a fist.
Open.

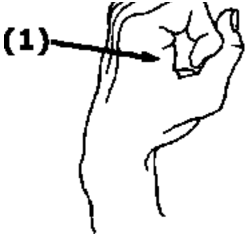


Figure

3. Make 'O's with the thumb and each finger.



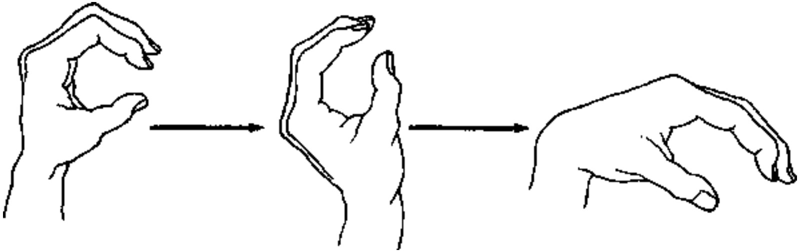
Figure



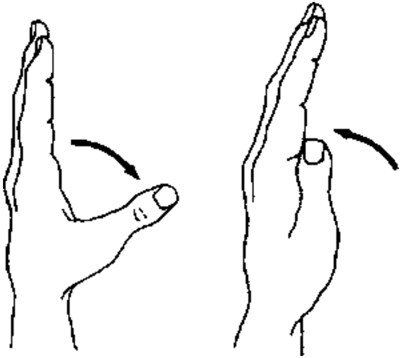
After you can make the large 'O's, repeat making the 'O' as small as you can. (1)

4. Bend wrist forward and backward. (Backward is more difficult but is especially important.)

5. Spread and close the thumb.



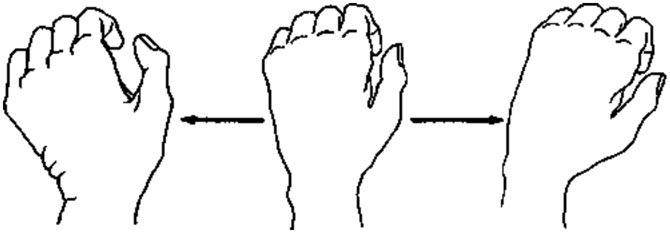
Figure



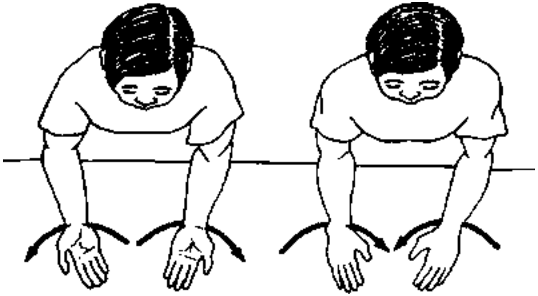
Figure

6. Bend the wrist from side to side.

7. Turn hands upward and downward-as far as you can.



Figure



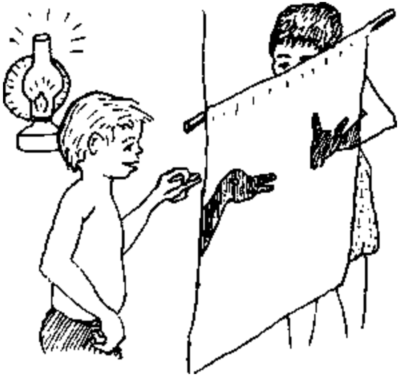
Figure

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.

Figure

Or play 'shadow puppets' with a light.

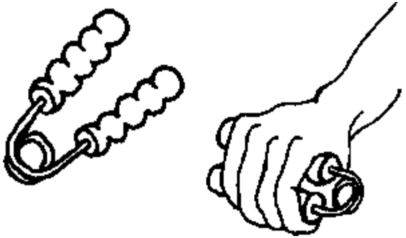


Figure

Aids for hand exercise

Figure

You can buy a simple hand exerciser like this.



Figure

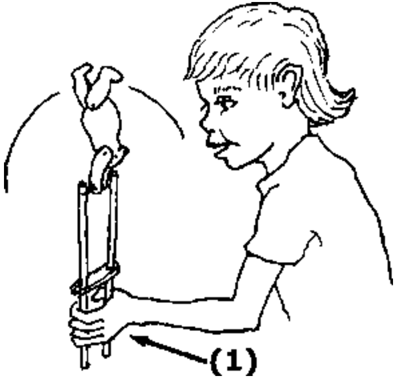
Or make one like this. If the child makes it herself, that will also be good exercise for her hands. (1)

Move this post forward or back to make it harder or easier to squeeze the aid. (2)

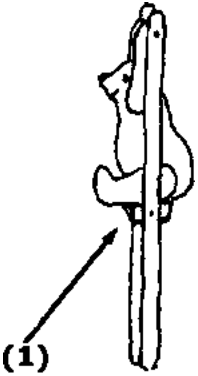
This ‘acrobatic bear’ is more work to make, but even more fun to exercise and play with.

Trace and cut out these pieces from wood or cardboard.

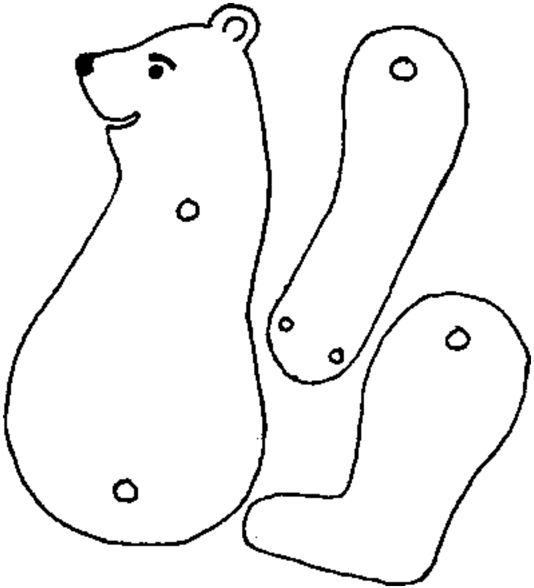
Fasten arms and legs loosely on body by putting a cord through holes.



Figure



Figure

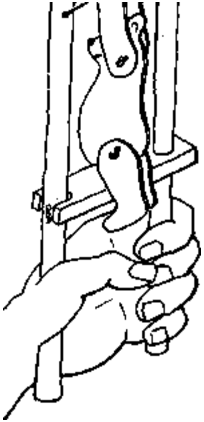


Figure

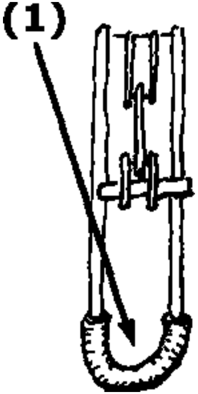
Squeezing the poles makes the bear ‘loop the loop’. (1)

“See if you can make the bear sit.” (1)

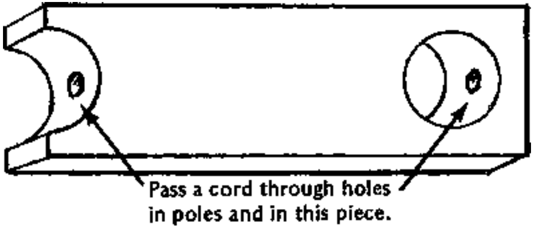
To have the child squeeze harder, attach a piece of rubber hose or car tire between the poles. (1)



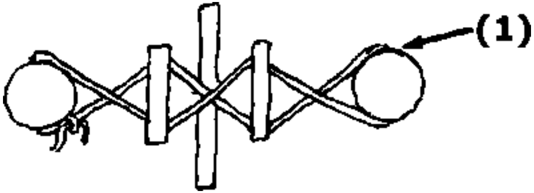
Figure



Figure



Figure



view from above showing how string passes through holes in poles and paws (1)

Figure

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 kinds of exercises are used for different disabilities, look under 'Exercises' in the INDEX.

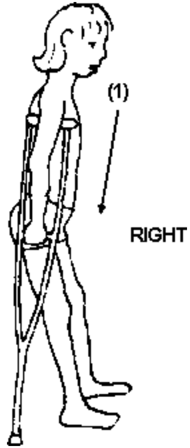
Chapter 43: Crutch Use, Cane Use, and Wheelchair Transfers

USE OF CRUTCHES

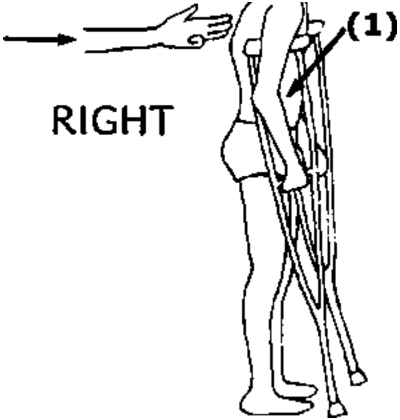
MAKING SURE THE CRUTCH FITS THE CHILD

When the child stands, the crutch should be 2 or 3 fingers' width below the armpit.

The elbow should be bent a little so that the child can lift herself up to swing her feet through. (1)

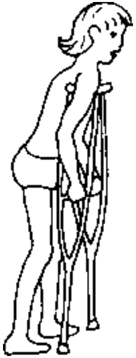
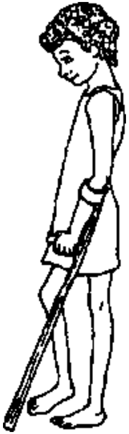


Figure



Figure

IMPORTANT Teach the child not to ‘hang’ on the crutches with her weight on her armpits. (1)	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.)

 **WRONG** In time, pressure on the nerves under the arm can cause **paralysis** of the hands.(1)  **Figure**	 **Figure**

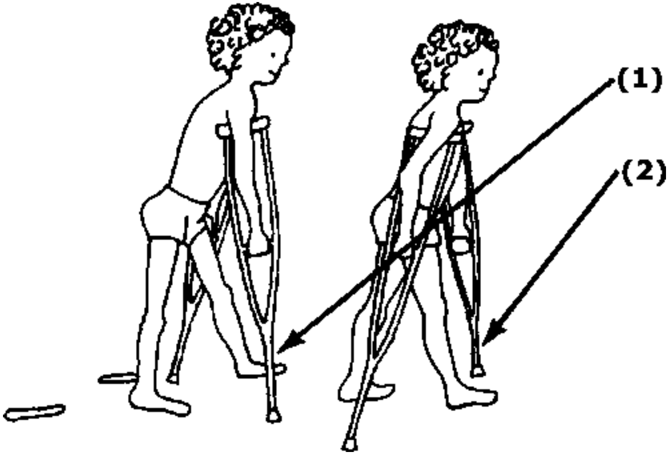
For designs and measurements of different crutches.

Walking with crutches

TAKING STEPS

Some children walk best by taking steps, one foot at a

For better balance and position, move the right crutch forward together with the left leg, and then the left crutch together with time.



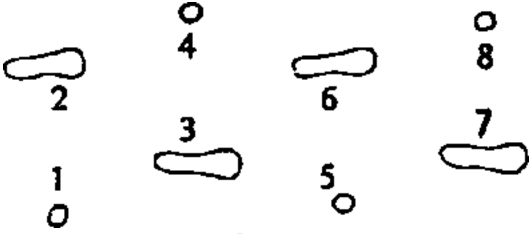
Figure

‘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.

the right leg. (1)

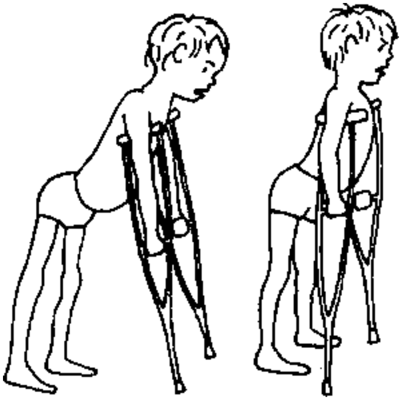
Her ‘tracks’ should look like this. (2)



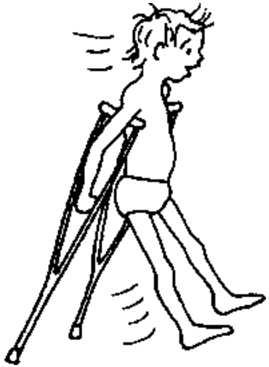
Figure

‘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 slow but sure.



This way is fast and fun.

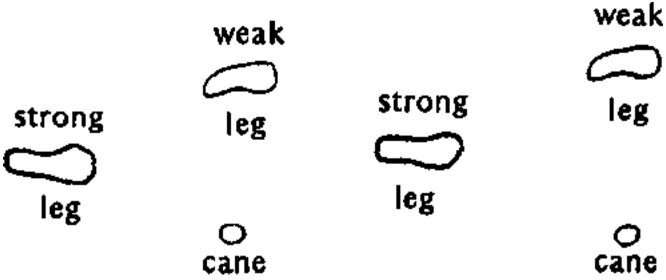
USE OF A CANE

It usually works best to hold the cane on the side opposite the weaker leg. (1)

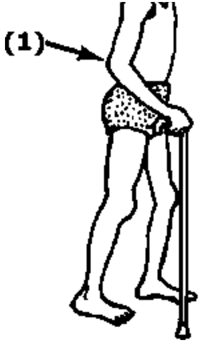
Move forward and put down the weaker leg and the cane together.

For different crutch and cane designs, see Chapter 63.

His ‘tracks’ should look like this.



Figure



Figure

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

Figure

WARNING: One disability can lead to another!

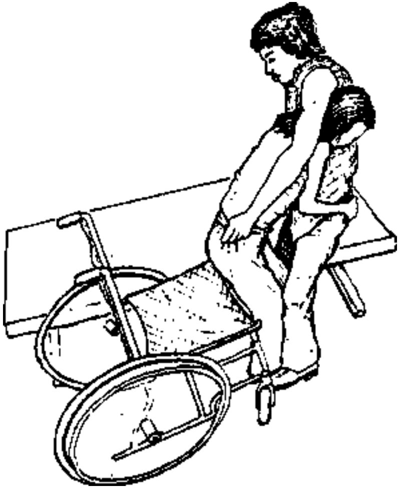
Notice that it is often easier to transfer sideways out of a chair, and also back into it. To transfer sideways, however, a *wheelchair without armrests,* or with at least one removable armrest, is needed. Therefore, for many disabled children, make an effort to get

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 she can.

Lift her like this and swing her onto the bed.



Figure

To lift him, grip his pants or make a canvas or leather sling.

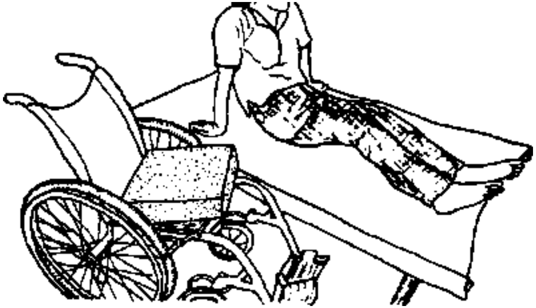
Figure

Ideas for wheelchair design, adaptation, and use are in Chapters 64, 65, and 66.

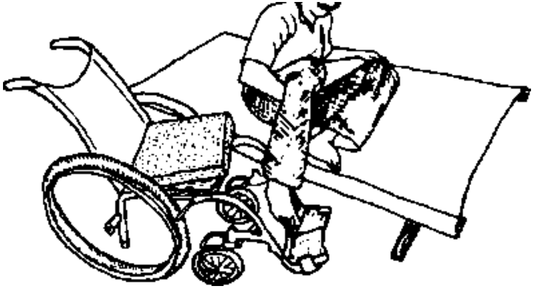
Transfer from cot or bed to wheelchair without armrests

***CAUTION:* Make sure brakes are ‘on’ and footrests are ‘up’ out of the way.**

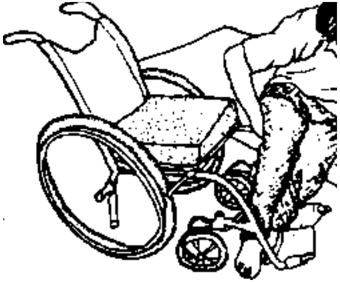
To transfer from the wheelchair to the cot, follow the same steps in reverse.



Figure



Figure



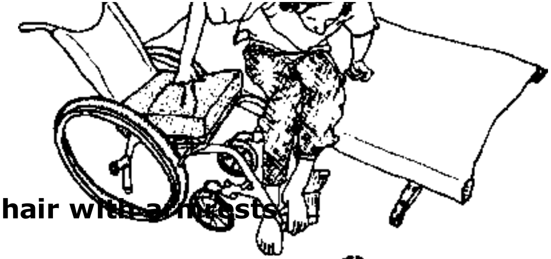
Figure

1. Push yourself to a sitting position.

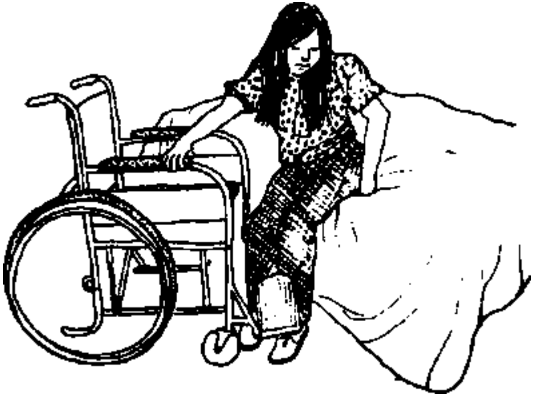
2. Reach under knees one at a time.

3. Move legs so that feet floor.

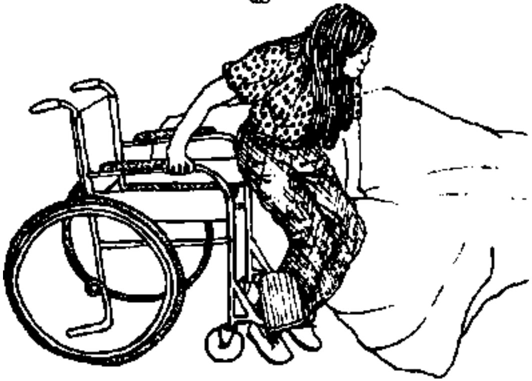
4. Make sure brakes are locked. Then push up on arms while leaning forward with head facing down. Weight should be over knees.



Transfer from cot or bed to wheelchair with armrests



Figure



Figure

Figure

1. Position your wheelchair so that

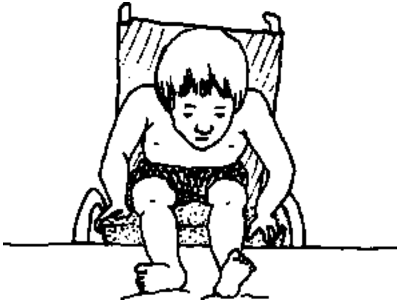
2. Place one hand on bed and one on

3. Swing body into wheel

you can swing body past armrests.

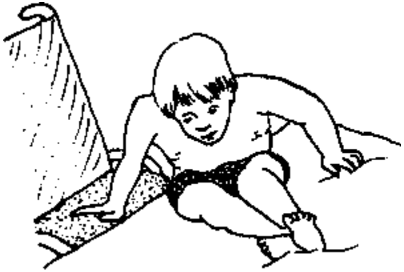
the far armrest. Push yourself up while leaning forward with head down, weight over knees.

Transfer forward from wheelchair to cot or bed (often works well for children)



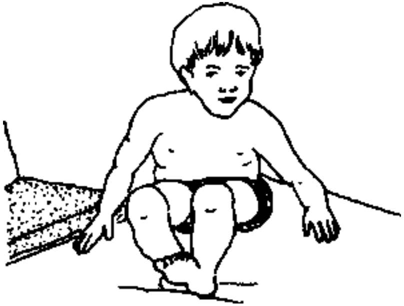
Figure

1. Lift feet onto bed and wheel the chair forward against bed. Put on brakes. Then bend forward and lift butt forward on chair.



Figure

2. With one hand on the cushion and one on the bed, lift the body sideways onto the bed.

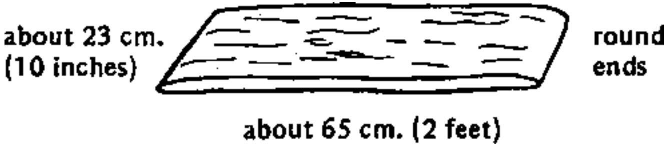


Figure

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.



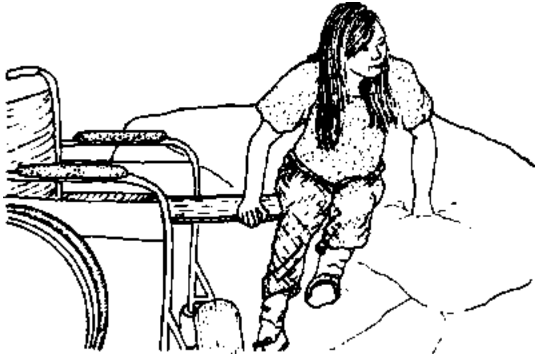
SLIDING BOARD

For getting into and out of bed, a car, etc.

Figure

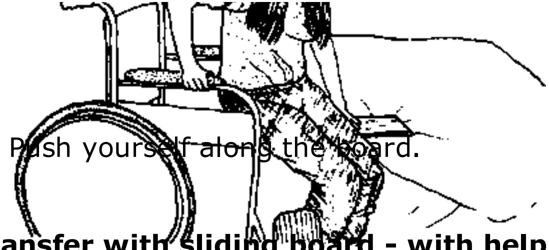
1. Place board under hip by leaning to opposite side or by pulling up leg.

SLIDING BOARD



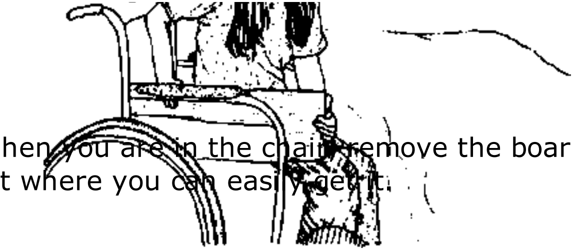
Figure

2. Lean forward, with your head and weight over knees.



Figure

3. Push yourself along the board.



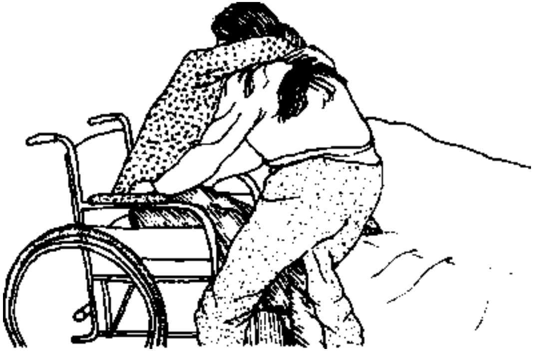
Figure

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

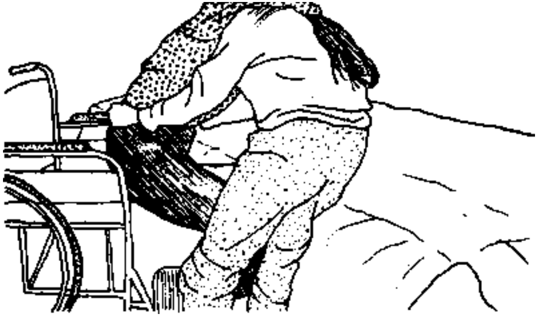
Figure

1. Lift leg and put board under hip.



Figure

2. Have person put arms around neck (if possible) while you put your hands under his ***butt,*** or grab his pants.

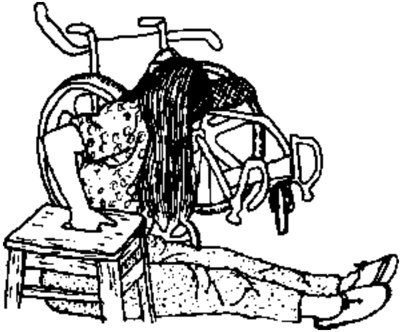


Figure

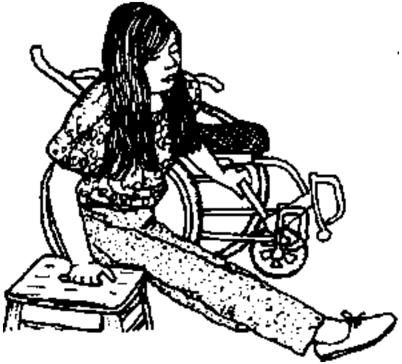
Figure

3. Slide the person along board to bed. 4. Lift legs onto bed.

Transfer from floor to wheelchair - with help of a low seat



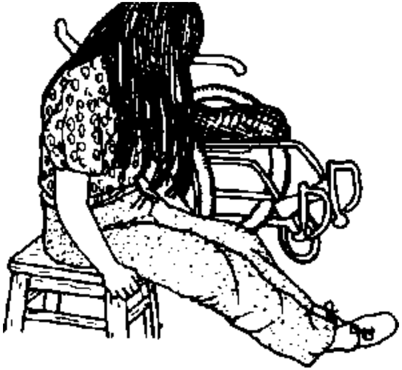
Figure



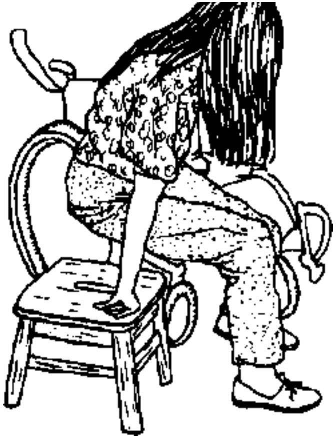
Figure

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.



Figure

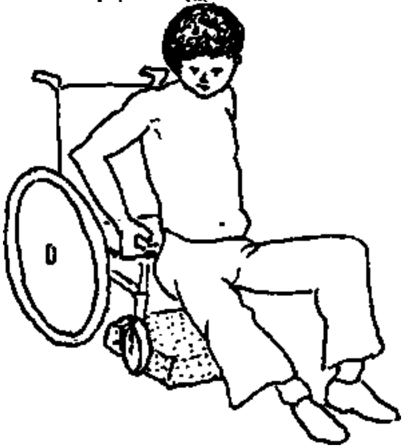


Figure

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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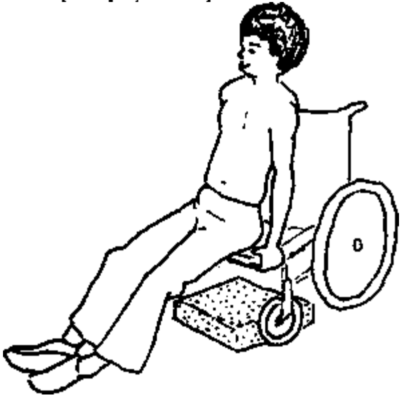

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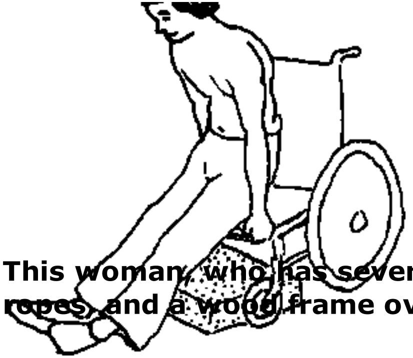

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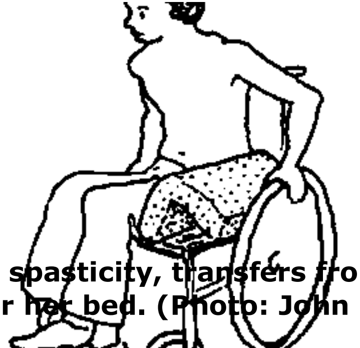

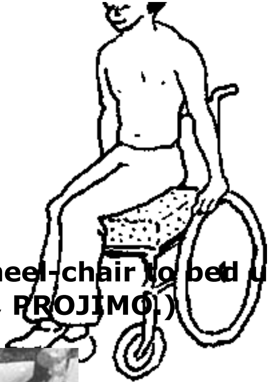

9

This woman, who has severe spasticity, transfers from wheel-chair to bed using tin cans, ropes, and a wood frame over her bed. (Photo: John Fago, PROJIMO.)

Figure

Figure

Figure