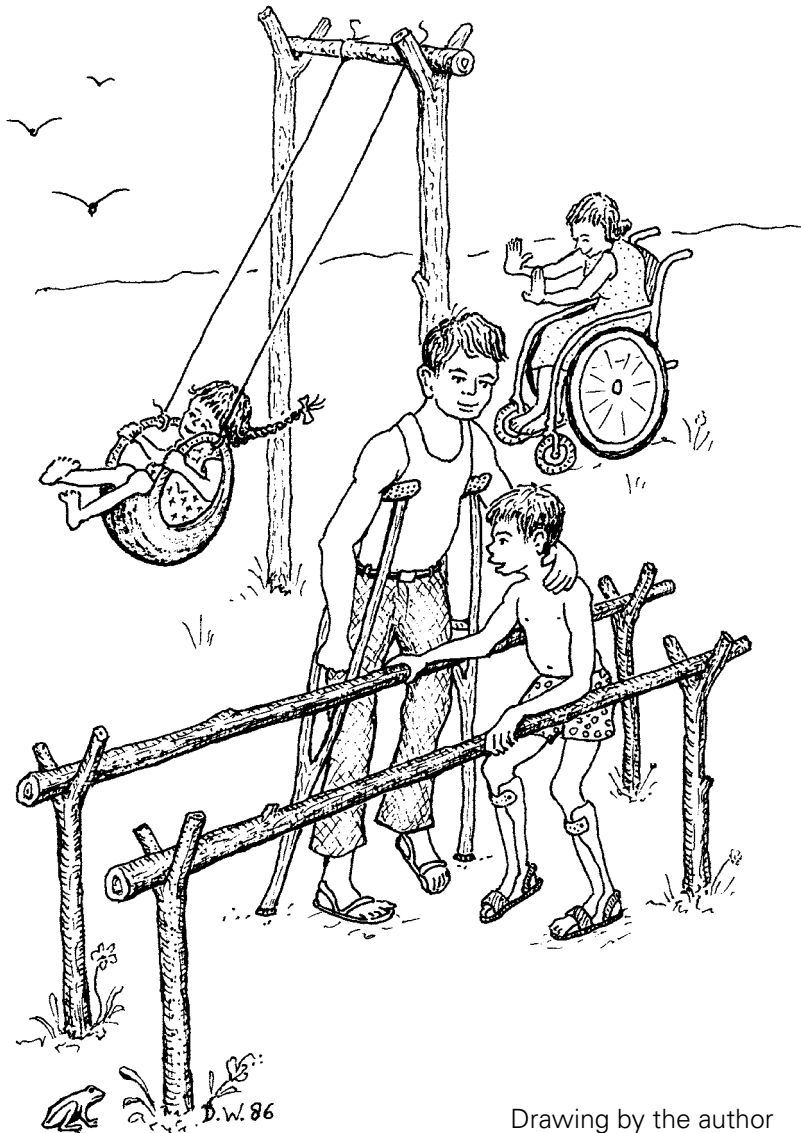


Disabled Village Children

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

By David Werner with the help of many friends



Drawing 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: 978-0-942364-06-4

PUBLISHED BY:

Hesperian Health Guides
2860 Telegraph Avenue
Oakland, California 94609
United States of America

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3rd edition, 12th printing, 2023

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This book is dedicated to children with disabilities 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 person with disabilities, parent, health worker, or rehabilitation therapist, to send us all your criticism and suggestions. Help us to make improvements for a later edition. Thank you.

WE WOULD APPRECIATE ANY
SUGGESTIONS YOU MAY HAVE
FOR WAYS THAT THIS BOOK
MIGHT BE IMPROVED TO SERVE
YOUR RURAL AREA BETTER.



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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 the disabled community. 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; M. 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; Valerie Taylor, PT; Dr. P. K. Sethi, orthopedic surgeon/prosthetist; Pam Zinkin, pediatrician/CBR expert; Paul Silva, wheelchair builder; David Morley, pediatrician; Elia Landeros, PT; Teresa Paez, social worker; Rafiq Jaffer, rehab specialist; Kris Buckner, parent of many adopted children with disabilities; 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; Donal Laub, plastic surgeon; Jean Kohn, MD in rehabilitation; Bob Friedrichs, 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 Goerdts, 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 Kgosia a, Garren Lumpkin, UNICEF.

Above all, we would like to thank the team of rehabilitation workers with disabilities in Project PROJIMO, Ajoya, Sinaloa, Mexico, along with the hundreds of children with disabilities 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 Álvarez, Adelina Bastidas, Roberto Fajardo, Teresa Gárate, Bruce Hobson, Concepción Lara, Inés León, Ramon León, Polo Leyva, Armando Nevárez, María Picos, Adelina Pliego, Eljio Reyes, Cecilia Rodríguez, Josefa Rodríguez, Concepción Rubio, Moisés Salas, Rosa Salcido, Asunción Soto, Javier Valverde, Florentino Velázquez, 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, Martin Bustos, Mary Klein, Carlos Romero and Marjorie Wang, paste-up; Martin Bustos and Anna Muñoz-Briggs, Spanish translation; Myra Polinger, typing; Lynn Gordon, Bill Bower, Phil Pasmanick and Dan Perlman, general review; Alison Davis, reference section research; Elizabeth de Ávila, Don Baker, Agnes Batteiger, Jane Bavelas, Leda Bosworth, Renee 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; Martin 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 with grants from the Public Welfare Foundation, whose continued friendship and support of the Hesperian's publications is deeply appreciated. Additional funding was generously provided by the Gary Wang Memorial Fund, UNICEF, OXFAM UK, the Swedish International Development Agency, MISEREOR, and May and Stanley Smith Charitable Trust. 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 updating this book, we thank Manisha Aryal, Asha Bajaj, Dani Behonick, John Bergez, Martin Bustos, Peg Cumberland, Darlena David, Digital Divide (Cambodia), Iñaki Fernández de Retana, Teresa Glass, Jacob Goolkasian, Shu Ping Guan, Todd Jailer, Namita Jacob, Yogesh Jain, Rosemary Jason, Aditi Malhotra, Jane Maxwell, Susan McCallister, Gail McSweeney, Elena Metcalf, Wendy Moya, Shruti Nishanth, Venkata Ranganadha Rao Pemmaraju, Naman Shah, C. Sienkiewicz, Kathleen Tandy, Dorothy Tegeler, Sarah Wallis, Amy Wilson, and Paula Worby.

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.

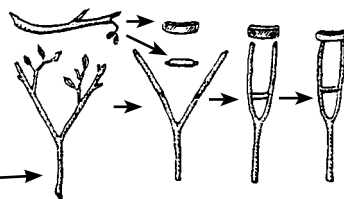
The health worker, who also had a physical disability, examined Pepe. "Have you ever tried to walk with crutches?" he asked. Pepe shook his head.

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

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



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

"I have an idea," said Pepe's father. He ran to a wild kapok tree, and picked several of the large ripe fruits. He gathered the soft cotton from the pods and put a cushion of kapok on the top crosspiece of each crutch. He wrapped 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.

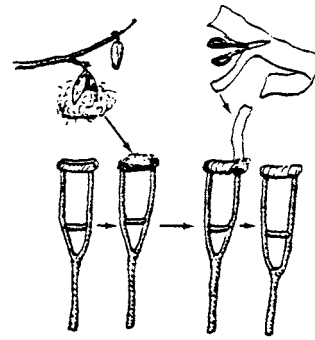
"I'm proud of you, son!" said his father, smiling too.

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."

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 craftsman."



"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!"

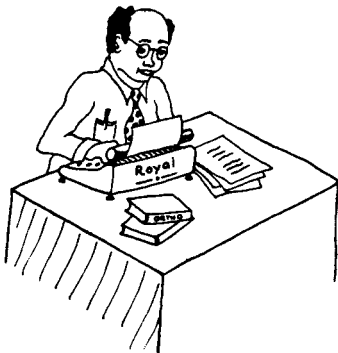
So the health worker learned many things from Pepe's father—things that he had never learned in school. He learned what kind of wood is best for making crutches. He also learned how important it is to use the skills and knowledge of the local people—because a better job can be done, and because it helps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

HOW THIS BOOK WAS WRITTEN

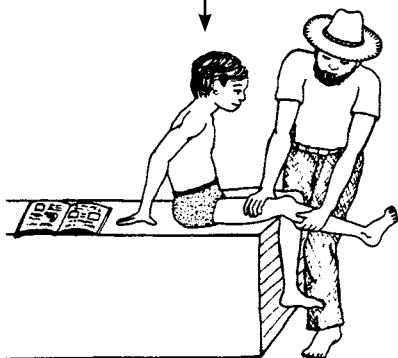
The story of Pepe's crutches is an example of the lessons we have learned that helped to create this book. We are a group of village health and rehabilitation workers who have worked with people in farming communities of western Mexico to form a villager-run rehabilitation program. Most of us on the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

From our experience of trying to help children with disabilities 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.

This book was not written by highly trained professionals



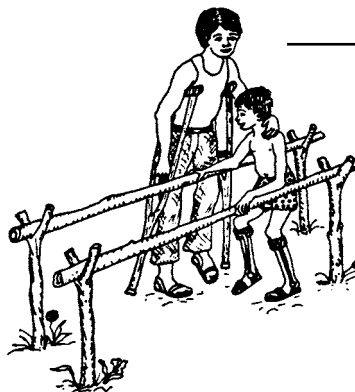
and then field tested with community workers.



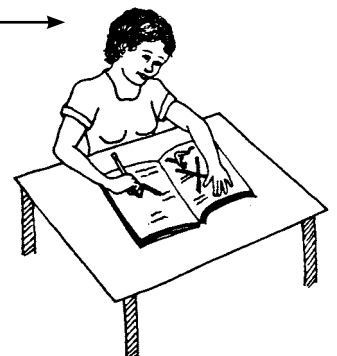
Unlike most handbooks for village workers and families, this book was not written by "professionals" and then field tested. Instead, it grew out of the practical experience of a team of village health workers with disabilities as we looked for information to help meet the most common problems we face.

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.

Instead, it was written by and with community workers,



and then reviewed by rehabilitation professionals.



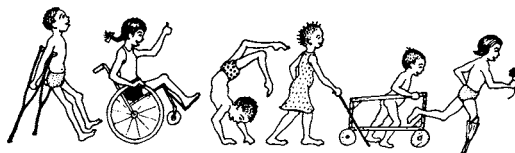
HOW THIS BOOK DIFFERS FROM OTHER REHABILITATION MANUALS

This book was written from within the communities it serves, working closely with people with disabilities 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 community. In fact, the main author of this book (David Werner) and many of its contributors happen to have disabilities. 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, people with disabilities are treated as objects to be worked upon, to be made as “normal” as possible. As people with disabilities, 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 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 planet that produces enough food for everyone but where many people go hungry. Where half of all people are denied access to the health care they need. Where the world’s leaders spend trillions of dollars every year on instruments of war instead of meeting people’s needs.

Instead of being “normalized” into such an unkind, unfair, and unreasonable social structure, we people with disabilities 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 people with disabilities, 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.



Rehabilitation manuals too often only give orders telling the local trainer, family member, and person with disabilities 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 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.

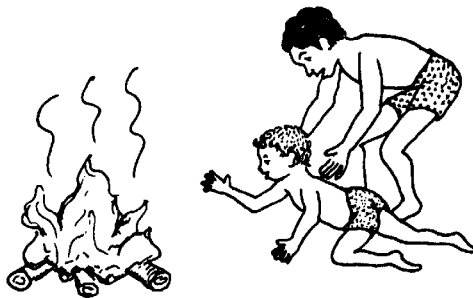
This is not the first handbook of “simplified rehabilitation.” We have drawn on ideas from many other sources. We would like to give special credit to the World Health Organization’s manual, *Training the Disabled in the Community (1980)*, and to UNICEF and Rehabilitation International’s *Childhood Disability: Prevention and Rehabilitation at the Community Level*, a shortened and improved version of the WHO manual. The WHO manual was rewritten in 1989 in a friendlier style that invites users to take more of a problem-solving approach instead of simply following instructions: *Training in the Community for People with Disabilities*.

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

WHICH DISABILITIES WE INCLUDED IN THIS BOOK

It is difficult to estimate how many of the world’s children have disabilities. Disability is defined and measured differently among countries. And how much a condition impacts a child’s ability to lead a full, active life can depend on where that child lives. The World Health Organization estimated in 2004 that 1 in 20 children 14 years old or younger live with a moderate to severe disability.

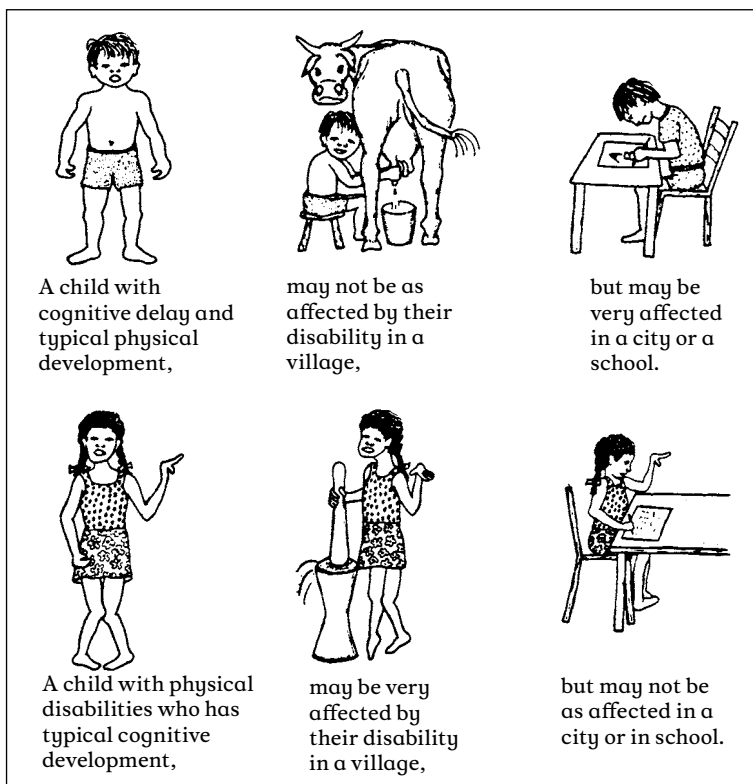
This book is written for use in many countries, and people in different parts of the world give importance to different disabilities. This is partly because some disabilities are more common in some places. Hearing loss and cognitive delay are more common in areas where the local diet is low in iodine. Problems seeing due to lack of vitamin A are common in communities with limited access to animal sources of food, and where children are frequently sick during childhood. Rickets is still common in regions where foods rich or fortified in vitamin D are not available, and there is limited skin exposure to sunlight due to geography, climate, and/or cultural practices. Burn injuries are frequent where people cook and sleep—and children play—on the ground near open fires.



In communities affected by HIV, many children are born to HIV-infected mothers. When parents and babies are treated for HIV, children can survive and live with HIV (and many avoid getting HIV at all). But lack of treatment in children can cause them to become disabled. This book does not separately address illness and disability related to HIV, but many of the sections will be useful for children with HIV (assistive walking devices, child development, care for pressure sores, etc.). For more information, see *Helping Children Live with HIV* or a general health book like *Where There Is No Doctor* (see p. 642).

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 impairments 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 child with physical disabilities 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 child with cognitive delay who often has the hardest time.



The team of village workers with disabilities in Mexico soon realized that they also had to learn about other disabilities. Even children whose main disabilities were physical, like paralysis, were often held back by other (secondary) emotional, social or behavioral disabilities. And many children with brain injury not only had difficulties with movement, but also took longer to learn, had seizures, or had limited vision or hearing.

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 cognitive and developmental delay. Seizures (epilepsy) are also covered.

Loss of vision and loss of hearing are included, but only in a very brief 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 specific information that they need to be covered in separate books. Hesperian has since produced good instructional material on these disabilities. We list some of the best materials that we know in the References section (see p. 637).

Note: This book does not include disabilities which are mainly in the area of internal medicine, such as asthma, chronic lung or heart problems, severe allergies, diabetes, bleeding problems, cancers or HIV. And except for brief mention, it does not include very local disabilities such as lathyrism (parts of India). In local areas where these or other 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.

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 THE COMMUNITY VIEWS PEOPLE WITH DISABILITIES

A disability is a condition that causes a person to move, see, hear, learn, or understand differently from people without disabilities. A person's disability, in combination with their environment, may make it more challenging for them to live their daily life. How the community sees and treats children with disabilities is an important part of their environment. So are the supports and accommodations that can help people with disabilities manage better, which often require community effort or agreement.

Some local beliefs affect how people see and experience disabilities. In an area where people believe that seizures are the work of the devil, a child with seizures may be feared, teased or kept hidden. But in places where everyone accepts seizures as "just something that happens to certain people," a child who sometimes has seizures may participate fully in the day-to-day life of the community without being viewed as having a disability.

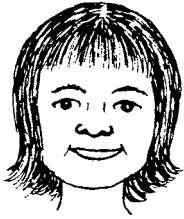
Consider how local people see and treat a child who is in some way "different." How do they accept or treat the child who takes longer to learn, limps a little or occasionally has seizures? If the community does not consider a child "disabled" and the child is able to manage well, it may be better not to identify her as "having a disability" while continuing to work with the family to help her manage better.

In many places, though, people with disabilities are ill-treated, bullied and discriminated against because of their disability. They are thought of as "different" or "other," and sometimes "not quite human." This discrimination may come from fears or other negative feelings and beliefs about disability held by people in the community, or even inside the person's family. Often people with disabilities have their own feelings and beliefs about disability that lead them to think of themselves in the same way that their community views them.

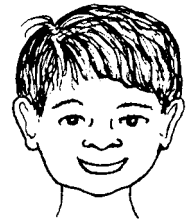
Some beliefs are extremely harmful. In some cultures, people believe that disabilities are caused by curses, are the result of bad behavior by a person or their family, or are contagious. As a result, people with disabilities may be denied opportunities to receive education or training or to participate socially in their community. Their families may become isolated, limiting their access to community support as well as jobs and income. This can have a lasting physical and emotional effect on people with disabilities and their families.

But when people work together to understand disabilities and include the experiences of people living with disabilities, it is possible to change incorrect views and ideas about them. It is also possible to find ways to bring greater understanding and acceptance of people with disabilities within the cultural reality of a community. No doubt this will be done in different ways in different places. For ideas about fostering greater understanding of the needs and capabilities of people with disabilities in local communities, see Chapter 44.





NOTE ON LANGUAGE USED IN THIS BOOK



Speaking of disabilities and people who have them

Language changes a lot as time passes. How we talk about disability changes as we understand more about the causes of disabilities, and how the words we use affect the people who experience them. You might notice that the words we use in this book to talk about specific disabilities, or disability in general, are not words you are familiar with. This may be because different words are used in different places in the world, or it may be because the language around disability has changed.



In this book, we talk about “children with disabilities” rather than “disabled children” (although the title of the book remains the same), because it is important to put the person first, not the disability. We try not to make assumptions about the lives of people with disabilities, so we talk about people “experiencing” disabilities rather than “suffering from” them. We have been mindful of language that would suggest that people with disabilities are less valuable or less important than people without disabilities. If there are places where our language still needs work, please let us know.

Speaking of children: “she,” “he,” and “they”

Literature on children with disabilities often speaks of the child as “he.” This is partly because male dominance is built into our language. It is also because boys with disabilities often receive better attention than do girls with disabilities. This is not surprising since, in many countries, boys without disabilities also get better treatment, more food, and more opportunities than girls without disabilities.

Because this adds to the continued oppression of children who are already disadvantaged, we have taken a different approach in this book. We sometimes refer to the child as “she,” and sometimes as “he,” and sometimes as “they.” We apologize if at times this is confusing. And if we sometimes slip and give more prominence to “he” than “she” or “they,” either in words or pictures, please let us know. We are working to change.

Speaking of the Author(s)

This book is a group effort. Although one person did most of the original writing, many shared in its creation and have contributed to its continued existence (see the “Thanks” page at the beginning of this book). Therefore, when speaking from the viewpoint of our authors and advisors, we usually use “we.”

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 formal education, together with children with disabilities 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 children with disabilities 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 children with disabilities.

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 people with disabilities. 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 people with disabilities, 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 craftsmen 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 people with disabilities, 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 girl with disabilities how to do stretching exercises of her hip to correct a contracture.

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, large numbers of children have disabilities from paralysis 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.

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 disabilities 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 occur 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 disability but commonly occur with other disability—usually with cerebral palsy—include seizures (Chapter 29), vision problems (Chapter 30), and hearing loss and communication difficulties (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.