Helping Children Who Are Blind

Family and community support for children with vision problems

Written by Sandy Niemann and Namita Jacob

Illustrated by Heidi Broner



Copyright © 2000 by The Hesperian Foundation. All rights reserved.

The Hesperian Foundation encourages others to copy, reproduce or adapt to meet local needs any or all parts of this book, including the illustrations, provided that the parts reproduced are distributed free or at cost—not for profit.

Any organization or person who wishes to copy, reproduce or adapt any or all parts of this book for commercial purposes must obtain permission from the Hesperian Foundation.

Before beginning any translation or adaptation of this book or its contents, please contact the Hesperian Foundation for suggestions about adapting the information in the book, updates on the information provided, and to avoid the duplication of efforts. Please send the Hesperian Foundation a copy of any materials in which text or illustrations from this book have been used.

First edition: September 2000. Printed in the USA. ISBN: 0-942364-34-1

Library of Congress Cataloging-in-Publication Data

Niemann, Sandy.

Helping children who are blind : family and community support for children with vision problems / written by Sandy Niemann and Namita Jacob; illustrated by Heidi Broner -- 1st ed.

p. cm.

ISBN 0-942364-34-1 (paper)

1. Children, Blind -- Family relationships. 2. Visually handicapped children -- Family relationships. 3. Children, Blind -- Services for. 4. Visually handicapped children -- Services for. 5. Child development. I. Jacob, Namita. II. Title.

HV1596.4.N54 2000 362.4'18'083-dc21

00-058209

Cover photograph by Namita Jacob of a blind boy and his sister in Vagash,Gujarat, India.

Cover art: anonymous tribal design, Orissa, India

The Hesperian Foundation PO Box 11577 Berkeley, California 94712-2577 United States of America

Credits and Thanks

The Hesperian Foundation is especially grateful to the committed health staff of Plan International. They have been important collaborators, sharing their understanding of the needs of parents and health promoters working with children. Plan International staff in Bangladesh reviewed and field-tested early versions of this book, improving it immeasurably. In addition, Plan's US member, Childreach, is generously helping fund the development of this series.

Project coordinator: Doreen Greenstein

Art coordination: Sandy Niemann

Design and production: Christine Sienkiewicz, Lora Santiago

Cover design: Christine Sienkiewicz

Additional writing: Doreen Greenstein, Sarah Shannon, Todd Jailer, Susan McCallister, Aryn Faur

Research assistance:

Kinkini Banerjee, Felicia Lester, Amina LaCour Mini, Rebecca Ratcliff, Nicolle Perez, Shana Nelson, Karen Cook **Production management:** Susan McCallister

Field-testing and networking: Estelle Schneider, Denise Bergez, Rebecca Ratcliff, Sofia Betancourt

Additional illustrations: Christine Sienkiewicz, Lora Santiago, Petra Röhr-Rouendaal

Additional production: Sofia Betancourt, Nicolle Perez

Copy editing: Jane Maxwell

Proofreading: Lorraine Mann **Editorial oversight:** Todd Jailer

A special thanks to all the funders of this book and the Early Assistance Series:

Childreach, the US member of Plan International DANIDA - Royal Danish Ministry of Foreign Affairs Frank Edwards Morgan Hill Lions Club The Presiding Bishop's Fund for World Relief (Episcopal Church) Scales of Justice Lions Club May and Stanley Smith Charitable Trust United Nations Children's Fund (UNICEF) United Nations Voluntary Fund on Disability

Credits and Thanks

Field Test Sites

This book was developed in collaboration with grassroots organizations and parents groups around the world. We gratefully acknowledge the contribution of those involved in the field-testing process:

Arthur Blaxall School, South Africa	National Association of the Blind, India
Association of Early Intervention, Czech Republic	Nepal Association for the Welfare of the
Belize Council for the Visually Impaired, Belize	Blind, Nepal
Blind Babies Foundation, USA	St. Lucia Blind Welfare Association,
Blind People's Association, India	St. Lucia
Community Disability Program, Institute of Child	Sight Savers International, Kenya
Health, UK	Special Education Organization, Islamic
Development Partners, Bangladesh	Republic of Iran
Hilton/Perkins Program, Thailand	Uganda National Institute of Special Education, Uganda
Jamaica Society for the Blind, Jamaica	Uganda Society for Disabled Children,
KAMPI (National Federation of Organizations of	Uganda
Persons with Disabilities), Philippines	Wa School for the Blind, Ghana
Institute for the Blind, South Africa	the benefit of the binne, channe
Laramara, Brazil	

Advisors and reviewers

This book was written with the guidance of many people around the world. We wish to express our thanks to the many advisors and reviewers who shared their knowledge and expertise:

We would like to thank the participants in the South Asian translators meeting (New Delhi, August, 2000), for their comments on "Chapter 12: Preventing Sexual Abuse." Thanks also to the Voluntary Health Association of India for permission to adapt the story on page 117 from their book, Child Abuse: A Growing Concern (1993).

Contents

Chapter 1: How Can I Help My Child?	
How children develop4	How you can help8
How vision problems affect development6	What about my child's future?9
Chapter 2: Getting Started	
How can this book help?11	Fitting activities into your daily life
Which activities should I do first?12	
Chapter 3: General Guidelines for Learnin	ng Activities15
You are the expert about your child 15	Let your child know what
Let your child take the lead15	is happening around him19
Adapt activities for your child16	Remember how children learn 20
Chapter 4: Finding Out What Your Child	Can See23
Is my child totally blind,	Helping your child
or can she see a little?24	use the sight she has
What does my child see? 25	Will my child's sight get worse? 30
Chapter 5: Activities for the Young Baby (
Birth to 3 months old32	4 to 6 months old 40
Chapter 6: Communication	
How vision problems	Preparing to talk
affect communication	When your child begins to talk
Communicating before	Common problems
your child can talk	when learning to talk
Chapter 7: Thinking Skills	
Understanding objects60	Solving problems64
Doing the same	Matching and sorting objects
things others do (imitation)62	Counting 67
Understanding why things happen (cause and effect)63	Increasing your child's thinking skills 68
Chapter 8: Teaching Everyday Activities	
Taking care of himself71	Dressing78
Helping with your family's work	Using the toilet or
Being well-behaved73	latrine (toilet training)
Eating74	Keeping clean84
Chapter 9: Safety	
To help your child	To make the area
move about the house 85	outside your home more safe

Chapter 10: Movement		89
Activities to help your	Helping your child learn to stand	92
baby move by himself 90	Hand and finger skills	98
Chapter 11: Helping Your Child Know W	here She Is (Orientation)	101
How a child learns	Touch and feeling	108
to know where she is102	Smell	110
Sight 105	Other orientation skills	111
Hearing 106	How the community can help	114
Chapter 12: Preventing Sexual Abuse		115
Some facts about sexual abuse 116	Preventing sexual abuse	119
Sexual abuse has lasting effects 117 Why is my child at	How can I know if my child has been sexually abused?	123
risk for sexual abuse? 118	To make all the children in the community safer	
Chapter 13: Becoming Part of the Comm	unity	125
How community members can help 126	Community projects	
How other children can help127	Playground suggestions	
Chapter 14: Getting Ready for Child-care	and School	135
Preparing for child-care and school 135	Learning to read and write Braille	
Preparing the school for your child 137	School is important for all children	
Preparing to read and write		
Chapter 15: Support for Parents and Caregivers		141
When you first learn	Be realistic	
your child cannot see well 142	The power of parents	
Managing the stress of caregiving 144	working together	147
Chapter 16: Why Children Lose Their Vis	ion and What We Can Do	155
Causes of blindness	Other ways to prevent blindness	166
and eye problems156	How can people work together	
Traditional beliefs and eye medicines 165	to prevent blindness?	
Chapter 17: As Your Child Gets Older		169
When your child realizes he is blind 169	Continuing to solve problems	173
Helping your child with his feelings 170	Thinking about the future	174
Balancing dependence and independence172	Using your experience to help others	
Appendix A: Child Development Charts		176
Appendix B: Toys You Can Make		184
Where to Get More Information		188

HOW TO USE THIS BOOK

When using this book, try to read Chapters 1 through 4 first. These chapters have important background information on how to help your child learn. Then turn to Chapters 5 through 8, and Chapters 10 and 11, to find examples of activities to help your child learn new skills.

The remainder of this book contains information to help caregivers support one another, to help parents learn from one another and work together, and to increase your knowledge of blindness and vision problems.

ABOUT THE PICTURES

Since this book was written for people around the world who care for children with vision problems, the drawings show people from many cultures. We hope these drawings will remind you that people all over the world face the same challenges you do.

A NOTE ABOUT THE LANGUAGE WE USE IN THIS BOOK

Most books about children who are blind talk about the children as if they are all boys and use the word "he" to refer to any child. This happens because society holds men to be more important than women and that belief is built into our language.

In fact, girls are not only left out of our language, they often receive less attention and care as well. This can include getting less food and getting less health care —

both of which contribute to blindness.

In a small way, we have tried to reflect a more equal world

by using both "he" and "she" to refer to children. Because "he-or-she" is awkward, we use "he" in

some chapters and "she" in others.

Remember, all children need and deserve our love and support.



