

Hesperian Foundation and the contributors to *A Health Handbook for Women with Disabilities* do not assume liability for the use of information it contains. If you are not sure what to do about a problem, get advice and help from people with more experience or from local medical or health authorities.

This book provides basic information to help women with disabilities stay healthy, and will also help those who assist women with disabilities to provide good care. You can help us improve this health guide. So, if you are a woman with a disability, a caregiver, or anyone with ideas or suggestions about how to improve this book and the health of women with disabilities, please write to us. We would like to hear about your experiences and practices.

Copyright © 2007 by Hesperian Foundation. All rights reserved.

First edition: February 2007

Printed in the USA

ISBN: 978-0-942364-50-7 paper

Library of Congress Cataloging-in-Publication Data

Maxwell, Jane, 1941-

A health handbook for women with disabilities / Jane Maxwell, Julia Watts Belser, and Darlena David.

p. cm.

Includes index.

ISBN 0-942364-50-3

1. Women with disabilities--Health and hygiene. 2. Women with disabilities--Medical care. I. Belser, Julia Watts, 1978- II. David, Darlena. III. Title.

RA654.88.M39 2006

613'.04244--dc22

2006049246

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 Hesperian Foundation.

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



1919 Addison Street, #304
Berkeley, California 94704, USA

CREDITS

Art coordination:

Jane Maxwell

Community review coordination:

Jane Maxwell and Sarah Constantine

Project support:

Soo Jung Choi, Michelle Funkhauser,
Tawnia Queen, Heather Rickard,
Karen Wu

Design and production:

Jacob Goolkasian, Shu Ping Guan,
Christine Sienkiewicz,
Sarah Wallis

Cover design:

Iñaki Fernández de Retana,
Jacob Goolkasian, Sarah Wallis

Additional writing:

Pam Fadem, Judith Rogers,
Edith Friedman

Copy editing:

Kathleen Vickery, Todd Jailer

Indexing:

Victoria Baker

Proofreading:

Sunah Cherwin

Medical review:

Lynne Coen, Suzy Kim, Melissa Smith,
Susan Sykes, Sandra Welner

Editorial management:

Darlana David

Editorial oversight:

Sarah Shannon

Production management:

Todd Jailer

Artists:

Namrata Bali, Sara Boore, Heidi Broner,
May Florence Cadiante, Barbara Carter,
Gil Corral, Regina Faul-Doyle, Sandy
Frank, Shu Ping Guan, Jesse Hamm,
Haris Ichwan, Anna Kallis, Delphine
Kenze, Joyce Knezevitch, Sacha Maxwell,
Naoko Miyamoto, Lori Nadaskay,
Mabel Negrete, Gabriela Nuñez, Connie
Panzarini, Kate Peatman, Petra Röhr-
Rouendaal, Carolyn Shapiro, Ryan
Sweere, Sarah Wallis, Lihua Wang, David
Werner, Mary Ann Zapalac

Cover photo locations and photographers (left to right, counter-clockwise):

Uganda, Jan Sing
World Bank/Cambodia, Masaru Goto
Mexico, Suzanne C. Levine
India, Amy Sherts
Bulgaria, Sean Sprague/SpraguePhoto.com
World Bank/Uzbekistan, Anatoliy
Rakhimbayev

Back cover

Uganda, UMCOR-ACT International,
Paul Jeffrey
Bangladesh, Jean Sack/ICDDR,B,
Courtesy of Photoshare

Permissions:

We thank the following organizations
for permission to use their illustrations:
*Breast Health Access for Women with
Disabilities* at the Alta Bates Summit
Medical Center (for a drawing on page
130); Pearl S. Buck International, Vietnam
(for sign language drawings on pages
369-370); Sahaya International, USA (for
sign language illustrations drawn from
photographs in *The Kenyan's Deaf Peer
Education Manual*, on pages 369-370); and
Jun Hui Yang (for Chinese Sign Language
illustrations on pages 369-370).

THANKS

It is impossible to adequately thank all the people who helped make *A Health Handbook for Women with Disabilities* a reality. It started 10 years ago as a good idea shared by 2 women, and grew into a remarkable international collaboration between women with disabilities and their friends in more than 40 countries.

Listing a person's name does not begin to say how much her efforts and ideas helped create this book. Every staff member, intern, and volunteer here at Hesperian also helped bring this book into the world, including those who raise funds, manage finances, publicize our materials, and pack and ship them around the world.

Along with our tireless medical editors, we called on a few reviewers over and over again, and they deserve a special mention and our sincerest thanks: Naomi Ruth Esiaba, Kathy Martinez, Gail McSweeney, Janet Price, Judith Rogers, Andrea Shettle, Ekaete Judith Umoh, and Veda Zachariah.

Many thanks to the following groups of people with disabilities who contributed so much of their hearts, time, and personal experience to help us make sure the material in this book would be useful to women with disabilities all over the world:

- | | | |
|--|---|--|
| Afghanistan: the National Association of Women with Disabilities of Afghanistan (NAWDA) | Laos: the Lao Disabled People's Association, and the Lao Disabled Women Development Center | Tanzania: The National Council for People with Disabilities |
| Cambodia: the Women with Disabilities Committee of the Disability Action Council | Lebanon: the Arab Organization of Disabled People, and the National Association for the rights of Disabled People Lebanon (NARD) | Thailand: Disabled People's International-Asia Pacific |
| China: MSI Professional Services | Lesotho: the Lesotho National Federation of Organizations of Disabled | Trinidad/Tobago: the Tobago School for the Deaf, Speech and Language Impaired |
| Colombia: the Colombian Association for Disabled Peoples (ASCOPAR) | Mauritius: the Association of Women with Disability | Uganda: the Disabled Women's Network and Resource Organisation (DWNRO), Mobility Appliances by Disabled Women Entrepreneurs (MADE), and the National Union of Disabled Persons of Uganda |
| El Salvador: La Asociación Cooperativa de Grupo Independiente Pro Rehabilitación Integral (ACOGIPRI) | Nepal: the Nepal Disabled Women Society, and Rural Health Education Services Trust (RHEST) | USA: Mobility International USA (MIUSA), Through the Looking Glass, Women Pushing Forward, and the World Institute on Disability (WID) |
| Fiji: the Support Group for Women with Disabilities | Nigeria: the Family-Centered Initiative for Challenged Persons (FACICP) | Vietnam: the Vietnam Veterans of America Foundation |
| Finland: the Abilis Foundation, and The National Council on Disability | Palau: the Organization of People with Disabilities (Omekasang) | Yemen: the Arab Human Rights Foundation |
| Republic of Georgia: the Gori Disabled Club | Philippines: Differently Abled Women's Network (DAWN), Disabled People's International (DPI), and KAMPI | Zimbabwe: Disabled Women Africa (DIWA), the National Council on Disabled Persons of Zimbabwe, the Southern Africa Federation of the Disabled (SAFOD), and Women with Disabilities Development (ZWIDE) |
| India: the Amar Jyoti Charitable Trust, Blind People Association, Catholic Relief Services (CRS), Disabled People's International, Humane Trust, and Sanjeevini Trust | Russia: Perspektiva (the Regional Society of Disabled People) | |
| Jamaica: Combined Disabilities Association | South Korea: Korean Differently Abled Women United | |
| Kenya: The Bob Segero Memorial Project, and Hope | | |

Our heartfelt gratitude to everyone who gave so generously of their time and knowledge. Your commitment to health care for women with disabilities brought this book into the world.

| | | | | |
|-------------------|---------------------|---------------------|--------------------|---------------------|
| Caroline Agwanda | Roshni Devi | Deborah Kaplan | Winifred Mujesia | Rosemary Segero |
| Fatuma Akan | Tara Dikeman | Manali Kasbekar | Frank Mulcahy | Lonny Shavelson |
| Firoz Ali | Lori Dobeus | Susan Kaur | Irene Busolo | Maya Shaw |
| Janet Connatser | Pamela Dudzik | Christie Keith | Mwenesi | Julia Shelby |
| Allem | Shalini Eddens | Jennifer Kern | Dorothy | A.Shivasanthakumar |
| Eric Anderson | Sana Ali El-Saadi | Jahda Abou Khalil | Musakanya | Caroline Signore |
| Soc Balingit | Jennifer Fahnbulleh | Jackie | James Mwanda | Meenu Sikand |
| Florence Baingana | Nancy Ferreyra | Ndona Kingolo | Safia Nalule | Julia Simonova |
| Monica Bartley | Anne Finger | Pat Kirkpatrick | Sucheta Narang | Kathy Simpson |
| Denise Bergez | Lee Gallery | Kristi L. Kirschner | Kanika Sophak | Jan Sing |
| Rosangela Berman- | Monica Gandhi | Justine Kiwanuka | Nguon | Judith Smith |
| Bieler | Katherine Gergen | Mari Koistinen | Papa Djibril Niang | Florence Nayiga |
| Kim Best | Anita Ghai | Kathleen Lankasky | Cathy Noble | Ssekabira |
| Bimala Sharma | Eileen Girón Batres | BA Laris | Corbett O'Toole | Yvette Swan |
| Bhandari | Nora Groce | Ye Ja Lee | Deborah | Susan Sygall |
| Michael Blake | Heba Hagrass | Anne Leitch | Ottenheimer | Michael Tan |
| Cheri Blauwet | Maria Harkins | Cindy Lewis | Judy Panko Reis | Supatraporn |
| Joan Bobb-Alleyne | Phyllis Harshaw | Gertrude Likopo | Lauri Paolinetti | "Mai" Tanatikom |
| Claire Borkert | Sari Heifetz | Lesoetsa | Rafael Peck | Carolyn |
| Tina Bregvadze | Karen Heinicke- | Rebecca C. Lim | Elizabeth Pearl | Thompson |
| Ron Brouillette | Motsch | Hoang Cam Linh | Penumaka | Uma Tuli |
| Arlene Calinao | Taija Heinonen | Sari Loijas | KP Perkins | Meldah B. |
| Cynthia | Susan Heller | Lizzie Longshaw | Minh Hang Pham | Tumukunde |
| Carmichael | Kevin Henderson | Josephine Lyengi | Allison Phillips | Doralee Uchel |
| Susan Canas | Judith Heumann | Annie Malinga | Judith Pollack | James Ullman |
| Silvia Casey | Rachael Holloway | Peggy Martinez | Jureeratana | Nance Upham |
| Phonesavanh | Rob Horvath | Rajaa Masabi | Pongpaew | Aruna Uprety |
| Chandavong | Ralf Hotchkiss | Melissa May | Zohra Rajah | Elizabeth Valitchka |
| Sivila Chanpheng | Honora Hunter | Katherine | Barbara Ridley | Koen Van Rompay |
| Sujith J. Chandy | Venus Ilagan | McLaughlin | Pia Rockhold | Jyoti Chandulal |
| Gladys Charowa | Namita Jacob | Joan McNeil | Denise Roza | Vidhani |
| Farai Cherala | Lisa Jensen | Lemnis Geraldo | Laura Ruttner | Zainab K. Wabede |
| Rosemary Ciotti | Usha Jesudasan | Mendez | Mariana Ruybalid | Jessica Mak Wei-E |
| Alicia Contreras | Kathy Al Ju'beh | Ruth Miller | Robert Sampana | Ann Whitfield |
| Ann Cupola | Rachel Kachaje | Linda D. Misek- | Beatriz Elena | Amy Wilson |
| Freeman | James G. Kahn | Falkoff | Satizabal | Dayna Wolfe |
| John Day | Wendy Kahn | Sruti Mohaptra | Marsha Saxton | Lin Yan |
| Kathryn Day | | Linda Mona | Estelle Schneider | |

We also want to thank and remember the following women who contributed so much, not only to this book, but to the community of women with disabilities around the world. Sadly, they died before the book was published: Hellen Winifred Akot, Tanis Doe, Ana Malena Alvarado, Connie Panzarini, Nanette Tver, Barbara Waxman-Fiduccia, and Sandra Welner.

We also thank the following foundations and individuals for their generosity in financially supporting this project: Alexandra Fund; Chaim Tovim Tzedakah Fund of the Shefa Fund; Christopher Reeve Paralysis Foundation; Displaced Children and Orphans Fund/ Leahy War Victims Fund, U.S. Agency for International Development (under terms of JHPIEGO contract no. 06-TSC-022); Flora Family Foundation; Ford Foundation; Global Fund for Women; James R. Dougherty Jr. Foundation; Jennifer Kern; Kadoorie Charitable Foundation; Margaret Schink; Marguerite Craig; Marji Greenhut; May and Stanley Smith Charitable Trust; Norwegian-Dutch Trust Fund for Gender Mainstreaming/World Bank; Swedish International Development Agency; and the West Foundation.

CONTENTS

Introduction: Why a book about health for women with disabilities?.....1

1. Disability and the community5

| | | | |
|---------------------------|----|------------------------------------|----|
| What is disability?..... | 6 | Wrong ideas about disability | 15 |
| Causes of disability..... | 10 | Working for change | 16 |

2. Organizing for disability-friendly health care29

| | | | |
|---|----|---|----|
| Root causes of problems..... | 31 | Learning about disability..... | 41 |
| Health care is a human right for all..... | 33 | Helping women with particular disabilities | 43 |
| Making health services easier to use..... | 35 | Working for change | 44 |
| Make buildings easier to use..... | 38 | | |

3. Mental health49

| | | | |
|----------------------------------|----|--|----|
| Challenges to mental health..... | 50 | Serious mental illness (psychosis) | 59 |
| Depression..... | 54 | Working towards mental health | 60 |
| Trauma..... | 56 | Forming support groups..... | 65 |

4. Understanding your body.....71

| | | | |
|---|----|--|----|
| When a girl's body starts to change (puberty)..... | 71 | A woman's reproductive system | 77 |
| Monthly bleeding (menstruation) | 74 | Infertility | 81 |
| | | Creating a family through adoption | 83 |

5. Taking care of your body85

| | | | |
|----------------------------------|-----|--|-----|
| Eat well for good health | 86 | Monthly bleeding | 109 |
| Keep your body moving..... | 88 | Infections caused by yeast..... | 111 |
| Contractures..... | 94 | Pressure sores | 114 |
| Preventing common problems | 96 | Dysreflexia..... | 117 |
| Bladder control..... | 101 | Managing pain | 120 |
| Urinary infections | 105 | Working for change | 121 |
| Bowel control | 107 | Easier to use toilets and latrines | 123 |

6. Health exams.....125

| | | | |
|--|-----|-----------------------------------|-----|
| What regular health exams can tell you..... | 126 | The pelvic exam | 130 |
| The breast exam | 128 | Other exams to stay healthy | 135 |
| | | Working for change | 136 |

7. Sexuality139

| | | | |
|---|-----|------------------------------------|-----|
| Harmful beliefs about disabled women's sexuality | 140 | Different ways of having sex..... | 147 |
| Learning about sexuality..... | 142 | Possible problems during sex | 151 |
| | | Working for change | 154 |

8. Sexual health: preventing sexually transmitted infections including HIV/AIDS157

| | | | |
|--|-----|------------------------------------|-----|
| Trichomonas..... | 159 | What is HIV/AIDS..... | 169 |
| Gonorrhea and chlamydia | 160 | Treatment for HIV/AIDS | 176 |
| Sores on the genitals..... | 163 | Preventing infection at home | 179 |
| Genital herpes and genital warts | 165 | Safer sex..... | 180 |
| Hepatitis | 167 | Working for change | 182 |

| | |
|--|------------|
| 9. Family planning | 185 |
| How family planning works | 187 |
| Barrier methods | 189 |
| Intra-Uterine Devices (IUDs) | 195 |
| Hormonal methods | 196 |
| Birth control pills..... | 197 |
| Breastfeeding..... | 199 |
| Natural family planning | 200 |
| Sterilization..... | 203 |
| Emergency methods | 205 |
| Abortion | 207 |
| 10. Pregnancy..... | 209 |
| Planning for pregnancy and birth..... | 213 |
| Staying healthy | 215 |
| The 9 months of pregnancy | 217 |
| Discomfort during pregnancy | 220 |
| Movement and balance | 222 |
| Muscle cramps | 225 |
| Aches and pains in the joints | 228 |
| Common health problems..... | 230 |
| Toxemia of pregnancy | 232 |
| Working for change | 233 |
| 11. Labor and Birth..... | 235 |
| How to tell you are in labor | 236 |
| How to make labor easier | 240 |
| Birth by operation (Cesarean) | 244 |
| Danger signs during labor..... | 245 |
| Danger signs after birth | 247 |
| Care for a new mother..... | 249 |
| Care for a new baby..... | 250 |
| Working for change | 251 |
| 12. Caring for Your Baby | 253 |
| Breastfeeding..... | 255 |
| Feeding an older baby | 265 |
| Comforting the baby | 266 |
| Changing and dressing the baby | 268 |
| Cleaning the baby | 269 |
| Carrying and moving the baby..... | 271 |
| Protecting children’s health..... | 274 |
| Immunizations | 276 |
| 13. Growing older with a disability | 277 |
| Health problems caused by aging | 278 |
| Find new ways to do things | 281 |
| When monthly bleeding stops..... | 282 |
| Live an active life | 285 |
| 14. Abuse, violence, and self-defense..... | 287 |
| Emotional abuse | 290 |
| Physical abuse | 294 |
| Preventing abuse..... | 295 |
| Leaving violent partners..... | 297 |
| Sexual abuse..... | 298 |
| Health problems caused by rape | 302 |
| Abuse in institutions | 306 |
| Self-defense | 308 |
| 15. Support for Caregivers..... | 313 |
| Value caregivers..... | 315 |
| Caregivers need help too..... | 317 |
| Take care of yourself..... | 319 |
| Start a caregiver’s group | 321 |
| Green Pages..... | 327 |
| How to take medicines safely | 327 |
| Taking other medicines with your disability medicines | 328 |
| Kinds of medicine..... | 330 |
| Problem List | 331 |
| Oral contraceptives | 355 |
| Emergency family planning | 357 |
| Medicines for AIDS (ART) | 358 |
| Appendix A: Take care of your equipment | 363 |
| Hearing aids | 363 |
| Using a stick to get around..... | 365 |
| Taking care of your wheelchair..... | 366 |
| Appendix B: Sign language for health | 369 |
| List of difficult words | 372 |
| To learn more | 375 |
| Index..... | 385 |

Introduction



Why a book about health for women with disabilities?

Women with disabilities need good health. Good health is more than the absence of disease. When a disabled woman has good health it means she experiences well-being—of her body, mind, and spirit.

Women with disabilities can take charge of their own health when they have information that affirms their own experience of their bodies and health needs. They can also use this information to change the way people think about disability. As women with disabilities take charge of their lives, they will gain respect and support in their communities.

While disability itself may not be a health problem, many times the health problems of women with disabilities go untreated. This can mean that a simple health problem in a woman with disability, if left untreated, can become a life-threatening problem.

We must remove the barriers that keep disabled women from achieving good health.

In my country, the disabled, and especially disabled women, are seen as children, and you don't give children any responsibility. So women with disabilities get excluded from almost everything: education, health care, land ownership, etcetera.

We need information for women with disabilities so that they can learn how to take better care of their health themselves, to learn what they can do as a community to get doctors and nurses and hospital administrators to change their attitudes and make health care more accessible and available for women with disabilities.



—Lizzie Longshaw,
National Council of Disabled
Persons of Zimbabwe

BARRIERS TO GOOD HEALTH CARE

Like most women, women with disabilities often find it difficult to get the health care they need, when they need it.

Even if a woman lives near a health center and has enough money to pay for services, most clinics, health centers and hospitals have not been designed to make it easy for everyone to use them. Disabled women find barriers to care when health facilities do not have ramps for wheelchair users, do not have information in Braille or on audio cassettes for blind or vision-impaired people, do not have sign language interpreters for women who are deaf, and do not have people who can assist women who have trouble learning or understanding.

Another problem is that doctors and other health workers are not usually trained to understand the health needs disabled women may have. Because of this, health workers may have ideas about disability that make it uncomfortable and hard for disabled women to get good health care.

When women with disabilities do not have access to resources, education, and other opportunities, they are more vulnerable to poverty, exploitation, and abuse. Without confidence in and awareness of their rights, they are often socially marginalized. This creates even more barriers to their access to health care.

WHO THIS BOOK IS FOR

This book is written for the millions of women with disabilities around the world who suffer and die needlessly because they lack access to respectful and appropriate health care.

This book can help most women with disabilities better care for themselves, improve their general health, their capabilities and self-reliance, and their ability to participate more effectively in their communities.

This book is not a rehabilitation manual and does not have all the information needed to diagnose and treat different kinds of disease, sickness or disability. The book has other goals.

This book gives information about the ways a disability may make the health needs of a woman with a disability different from those of a woman who does not have a disability.

The information in the book will help women with disabilities get better care from others.

This book will help health workers, as well as family members and caregivers, learn that disability by itself does not mean sickness, but that a woman with a disability—a blind woman, or a woman who uses a wheelchair—may have illnesses such as HIV/AIDS or malaria, just like women who do not have disabilities.

This book will help families, friends, community health workers, and other people who assist women with disabilities to be partners in caring.

This book also has information about the social causes of disability, and suggests ways to help change feelings and beliefs that are harmful to the health of women with disabilities, their families, and their communities.

To make the book as useful as possible, women with disabilities around the world shared their health needs, beliefs, and practices, and told us what they would most like included in the book. Their voices, experiences, and stories helped shape the writing and are reflected on every page.



