

# A Health Handbook for **Women with Disabilities**

Jane Maxwell, Julia Watts Belser, and Darlena David



Berkeley, California, USA

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)

**Cambodia:** the Women with Disabilities Committee of the Disability Action Council

**China:** MSI Professional Services

**Colombia:** the Colombian Association for Disabled Peoples (ASCOPAR)

**El Salvador:** La Asociación Cooperativa de Grupo Independiente Pro Rehabilitación Integral (ACOGIPRI)

**Fiji:** the Support Group for Women with Disabilities

**Finland:** the Abilis Foundation, and The National Council on Disability

**Republic of Georgia:** the Gori Disabled Club

**India:** the Amar Jyoti Charitable Trust, Blind People Association, Catholic Relief Services (CRS), Disabled People's International, Humane Trust, and Sanjeevini Trust

**Jamaica:** Combined Disabilities Association

**Kenya:** The Bob Sehero Memorial Project, and Hope

**Laos:** the Lao Disabled People's Association, and the Lao Disabled Women Development Center

**Lebanon:** the Arab Organization of Disabled People, and the National Association for the rights of Disabled People Lebanon (NARD)

**Lesotho:** the Lesotho National Federation of Organizations of Disabled

**Mauritius:** the Association of Women with Disability

**Nepal:** the Nepal Disabled Women Society, and Rural Health Education Services Trust (RHEST)

**Nigeria:** the Family-Centered Initiative for Challenged Persons (FACICP)

**Palau:** the Organization of People with Disabilities (Omekasang)

**Philippines:** Differently Abled Women's Network (DAWN), Disabled People's International (DPI), and KAMPI

**Russia:** Perspektiva (the Regional Society of Disabled People)

**South Korea:** Korean Differently Abled Women United

**Tanzania:** The National Council for People with Disabilities

**Thailand:** Disabled People's International-Asia Pacific

**Trinidad/Tobago:** the Tobago School for the Deaf, Speech and Language Impaired

**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

**USA:** Mobility International USA (MIUSA), Through the Looking Glass, Women Pushing Forward, and the World Institute on Disability (WID)

**Vietnam:** the Vietnam Veterans of America Foundation

**Yemen:** the Arab Human Rights Foundation

**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)

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

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 community .....5

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

### 2. Organizing for disability-friendly health care .....29

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 health .....49

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 body .....85

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. Sexuality .....139

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/AIDS .....157

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

<b>9. Family planning .....</b>	<b>185</b>
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
<b>10. Pregnancy.....</b>	<b>209</b>
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
<b>11. Labor and Birth.....</b>	<b>235</b>
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
<b>12. Caring for Your Baby .....</b>	<b>253</b>
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
<b>13. Growing older with a disability .....</b>	<b>277</b>
Health problems caused by aging .....	278
Find new ways to do things .....	281
When monthly bleeding stops.....	282
Live an active life .....	285
<b>14. Abuse, violence, and self-defense.....</b>	<b>287</b>
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
<b>15. Support for Caregivers.....</b>	<b>313</b>
Value caregivers.....	315
Caregivers need help too.....	317
Take care of yourself.....	319
Start a caregiver’s group .....	321
<b>Green Pages.....</b>	<b>327</b>
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
<b>Appendix A: Take care of your equipment .....</b>	<b>363</b>
Hearing aids .....	363
Using a stick to get around.....	365
Taking care of your wheelchair.....	366
<b>Appendix B: Sign language for health .....</b>	<b>369</b>
<b>List of difficult words .....</b>	<b>372</b>
<b>To learn more .....</b>	<b>375</b>
<b>Index.....</b>	<b>385</b>

