A Health Handbook for
Women with Disabilities

Jane Maxwell, Julia Watts Belser, and Darlena David
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

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.
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: Naomy 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 Segero 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.

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/ Leary 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; Marij Greenhut; May and Stanley Smith Charitable Trust; Norwegian-Dutch Trust Fund for Gender Mainstreaming/World Bank; Swedish International Development Agency; and the West Foundation.

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

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/ Leary 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; Marij 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
   Causes of disability .............................................................. 10

2. Organizing for disability-friendly health care ..........................................................29
   Root causes of problems .................................................. 31
   Health care is a human right for all ......................... 33
   Making health services easier to use ....................... 35
   Make buildings easier to use ........................................... 38

3. Mental health .............................................................................................................49
   Challenges to mental health ......................................... 50
   Depression ................................................................. 54
   Trauma ........................................................................... 56
   Serious mental illness (psychosis) .......................... 59
   Working towards mental health .............................. 60
   Forming support groups ............................................. 65

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

5. Taking care of your body ........................................................................................85
   Eat well for good health ............................................... 86
   Keep your body moving .............................................. 88
   Contractures .................................................................. 94
   Preventing common problems .............................. 96
   Bladder control ............................................................ 101
   Urinary infections ....................................................... 105
   Bowel control .............................................................. 107
   Monthly bleeding ...................................................... 109
   Infections caused by yeast .................................... 111
   Pressure sores ............................................................. 114
   Dysreflexia ................................................................. 117
   Managing pain ............................................................. 120
   Working for change ..................................................... 121
   Easier to use toilets and latrines ........................... 123

6. Health exams .......................................................................................................125
   What regular health exams can tell you ................... 126
   The breast exam ........................................................... 128
   The pelvic exam .......................................................... 130
   Other exams to stay healthy ................................... 135
   Working for change ..................................................... 136

7. Sexuality ...............................................................................................................139
   Harmful beliefs about disabled women’s sexuality ...... 140
   Learning about sexuality ........................................... 142
   Different ways of having sex .................................... 147
   Possible problems during sex ................................. 151
   Working for change ..................................................... 154

8. Sexual health: preventing sexually transmitted infections including HIV/AIDS ......157
   Trichomonas ................................................................. 159
   Gonorrhea and chlamydia ...................................... 160
   Sores on the genitals .................................................. 163
   Genital herpes and genital warts ........................... 165
   Hepatitis ................................................................. 167
   What is HIV/AIDS ..................................................... 169
   Treatment for HIV/AIDS ......................................... 176
   Preventing infection at home ................................ 179
   Safer sex ................................................................. 180
   Working for change ..................................................... 182
Family planning for women with disabilities (and their partners — whether able-bodied or disabled) must be made available. As is the case with the inclusion of persons with disabilities for all Millennium Development Goals, general reproductive health disabilities. Finally, women with disabilities face additional concerns that must be anticipated in Millennium Development Goal programming: (a) Contrary to the goals and principles of all the human rights conventions, women with disabilities and girls as young as 7 and 8 are often sterilized against their knowledge or will; (b) In some communities, women (and men) with disabilities who have children face the prospect of having their children taken from them because the parents have a disability.