

REFERENCES

(Where to Get More Information)

In the first edition of this book we included a list of references. In that list we gave the names of publications from which we borrowed information to use in this book. We also included books and materials which we did not use, but that we felt could be useful to other people.

Within this book, we give credit to authors whose materials we've used and also list several of them in these references pages. Since *Disabled Village Children* was written, many of the books that we recommended have gone out of print. This means that they are not published anymore. We continue to list several of them here because you may be able to find used copies. Where possible, we have updated the information of the organizations or publishers that distributed these books so you can contact them directly. If we know that an organization no longer exists, we have removed them from this section.

In this list we also include more organizations that offer information and materials on different disabilities. Some of them send free materials or offer them free online, but most charge some money for them. Contact them directly to get information on the type of books they sell and their prices. Be as precise as you can in explaining what you need so they can do a good job helping you.

You will notice that most of the organizations that we list here are in the United States but there are others in many different countries. Find out what kind of organizations or associations of people with disabilities exist where you are. It may be easier to get appropriate information and materials locally.

DISABILITY AND REHABILITATION—GENERAL

A Health Handbook for Women with Disabilities

J. Maxwell, J. Watts Belser, and D. David
Published by Hesperian Health Guides, see p. 642

Training in the Community for People with Disabilities

E. Helander, P. Mendis, G. Nelson, and A. Goerd
Published by World Health Organization,
Avenue Appia 20, 1211 Geneva 27, SWITZERLAND.
Tel: 41 22 791 2111, Fax: 41 22 791 3111,
publications@who.int, available online: <https://apps.who.int/iris/handle/10665/39065>

Very basic information—sometimes too basic. This latest edition has been improved, but it takes a rather top-down, authoritarian approach. Very simple language. Many pictures. Part of a total plan for a “community-based,” government-directed program.

Volver a Vivir/Return to Life S. Levine

Published by Hesperian Health Guides, see p. 642

A photographic report on the villager-run rehabilitation project, Project PROJIMO, in Mexico.

Special Needs Project 1000 E. Maple Avenue, Lompoc, CA 93436 USA. Tel: (805) 962-8087.

Fax: (805) 962-5087, books@specialneedsproject.com, www.specialneedsproject.com

A bookstore that sells by mail. It offers a great selection of books on many different disabilities and rehabilitation.

PRIMARY HEALTH CARE

Child-to-Child: A Resource Book

edited by D. Baily, H. Hawes, and G. Bonati.
Available from Health Books International
27a Albert Street, Rugby, Warwickshire, CV21 2SG
UNITED KINGDOM.
www.healthbooksinternational.org/
Activity sheets available free online:
<http://www.childtochild.org.uk/resources/mod/glossary/showentry.php?eid=9>

A guide to the Child-to-Child method of teaching about health, including Activity Sheets for teaching health education in an exciting way that can be adapted to the user's context.

Community-based Rehabilitation in the Bolivian Amazon

T. Glass Connaker
Available from Hesperian Health Guides, see p. 642

The story of one village's experience creating a community-based rehabilitation program, and a reference for other communities interested in this process.

Helping Health Workers Learn

D. Werner and B. Bower
Published by Hesperian Health Guides, see p. 642

Where There Is No Doctor

D. Werner
Published by Hesperian Health Guides, see p. 642

Where Women Have No Doctor

A. A. Burns, R. Lovich, J. Maxwell and K. Shapiro.
Published by Hesperian Health Guides, see p. 642



POLIO

Poliomyelitis: A Guide for Developing Countries—Including Appliances and Rehabilitation for the Disabled. R.L. Huckstep
Published by Longman, 1975, 279 pages.
(out of print)

This is an excellent book that went out of print. Very complete. Includes braces, assistive equipment, rehabilitation, and information for hospital care and surgery. Well adapted for poor countries and community programs. You may be able to locate a copy or use it online.

Post-Polio Health Newsletter (formerly *Polio Network News*).

Published by Post-Polio Health International
50 Crestwood Executive Ctr, Suite 440, St. Louis, MO 63126, USA.

Tel: (314) 534-0475, Fax: (314) 534-5070,
info@post-polio.org, www.post-polio.org

Quarterly report with international circulation. Focuses on long-term effects of polio. It promotes scientific research on polio and proposes the creation of a worldwide network of people with polio.

CEREBRAL PALSY

Finnie's Handling the Young Child with Cerebral Palsy at Home Edited by E. Bower

Published by Butterworth-Heinemann, 2009, 440 pages.
<https://www.sciencedirect.com/book/9780750688109/>

Excellent, complete and detailed information for home care. May be too much detail for some families—but a highly-recommended resource for a community program.

Treatment of Cerebral Palsy and Motor Delay.

S. Levitt and A. Addison
Published by John Wiley and Sons, Inc., 2018, 464 pages.
<https://onlinelibrary.wiley.com/doi/book/10.1002/9781119373902>

An advanced book, mostly on physiotherapy. Excellent information but difficult language and presentation. Many good pictures.

MUSCULAR DYSTROPHY

Muscular Dystrophy Association.
161 N. Clark, Suite 3550, Chicago, IL 60601 USA.
Tel: (800) 572-1717, resourcecenter@mdausa.org,
www.mda.org

Lots of pamphlets on all the different types of muscular dystrophy. This association can be very helpful for children who live in the United States because they provide, and can help find, many services. (Their main focus is finding a cure.)

ARTHRITIS

Arthritis Foundation.
1355 Peachtree St. NE, suite 600,
Atlanta, GA 30309 USA. Tel: (800) 283-7800,
www.arthritis.org

A great variety of written materials on the different aspects of several types of arthritis, including juvenile arthritis. Updated information on current research and medical treatment to function with and manage arthritis.

SPINA BIFIDA

Spina Bifida Association (SBA)
1600 Wilson Blvd., suite 800, Arlington, VA 22209 USA.
Tel: (800) 621-3141, sbaa@sbaa.org,
www.spinabifidaassociation.org

Basic information, especially useful for those who live in the USA and can access the care and services available. Contact SBA for a list of their materials.

SHINE: Spina bifida • Hydrocephalus • Information • Networking • Equality.

42 Park Rd, Peterborough, PE1 2UQ,
UNITED KINGDOM. Tel: 01733 555988,
info@shinecharity.org.uk, www.shinecharity.org.uk

Many publications on spina bifida and hydrocephaly are available from SHINE. Some of their materials are excellent.

SPINAL CORD INJURY

Tetraplegia and Paraplegia: A Guide for Physiotherapists.

I. Bromley
Published by Elsevier, 2006, 428 pages.
www.elsevier.com

Useful information on exercises, transferring, and how to shift weight to prevent pressure sores. Some good illustrations. Very technical.

Living with Spinal Cord Injury. Free PDF download.

English: www.hollister.com/-/media/files/pdfs-for-download/continence-care/hol_ccbl_living-w-sci_us_907500-112.ashx

Spanish: www.hollister.com/-/media/files/pdfs-for-download/continence-care/viviendo-con-una-lesion-en-la-medula-espinal_907640-712.ashx

Useful, accessibly written guide for people with spinal cord injuries and their families and caregivers. Many good illustrations. Sections include bowel and urine management, skin care, sexual adjustment, and others.

**EPILEPSY**

Seizures and Epilepsy in Children: A Comprehensive Guide

E.P.G. Vining and others
Published by Johns Hopkins University Press, 2022,
368 pages.
www.press.jhu.edu/books

Clearly explains many aspects of epilepsy in children. A good resource for families where a child has epilepsy. It can also be bought from the Epilepsy Foundation.

Epilepsy Foundation.

3540 Crain Highway, Suite 675, Bowie, MD 20716, USA.
Main Tel: (301) 459-3700;
24/7 Epilepsy and Seizures Helpline (800) 332-1000;
Tel for Spanish speakers: (866) 748-8008
www.epilepsy.com

An organization that offers a great collection of publications and videos on all the different aspects of epilepsy. These are educational materials, designed for individuals with epilepsy, their families, teachers, and society in general.

LEPROSY

The resources listed under this category are available from ILEP Federation, Avenue de France, 23, 1202 Geneva, Switzerland,
Tel: +41 22 710 08 57, Fax: +41 22 710 08 99,
ilep@ilepfederation.org, www.ilepfederation.org

These ILEP materials are available free online in English and French from <https://ilepfederation.org/about-leprosy/>

ILEP Learning Guide One: How to diagnose and treat leprosy (2019, 47 pages)

ILEP Learning Guide Two: How to recognize and manage leprosy reactions (2002, 62 pages)

ILEP Learning Guide Three: How to do a skin smear examination for leprosy (2003, 6 pages)

ILEP Learning Guide Four: How to prevent disability in leprosy (2006, 72 pages)

Triple Jeopardy (2015, 8 pages)

<https://ilepfederation.org/wp-content/uploads/2020/02/Triple-Jeopardy-IWD-2015.pdf>

A report on the discrimination facing women and girls with leprosy.

Guidelines on Stigma and Mental Wellbeing (2019)
ILEP and Neglected Tropical Disease NGO Network

A 4-part series sharing information on how stigma develops, how it can be reduced, and recommendations on assessing the experience of stigma and mental wellbeing.

VISION LOSS

Eye Diseases in Hot Climates.

J. Sandford-Smith

Published by The Ulverscroft Foundation
The Green, Bradgate Rd., Anstey, Leicester LE7 7FU,
UNITED KINGDOM
Tel: (44) 0116 2361595, www.ulverscroft-foundation.org.uk/about/our-publications.

A valuable resource (in English and French) for health programs. It teaches how to identify, prevent, and provide basic care for the most common eye diseases found in the tropics.

Helping Children Who Are Blind: Family and community support for children with vision problems.

S. Niemann and N. Jacob

Published by Hesperian Health Guides, see p. 642

Blind Children's Center

4120 Marathon Street, Los Angeles, CA 90029 USA
Tel: (323) 644-2153, www.blindchildrenscenter.org

This is an organization dedicated to serving children with vision loss 5 years of age and younger. They produce a lot of written materials for families of children with vision loss.

World Blind Union.

1929 Bayview Avenue, Toronto, Ontario M4G3E8,
CANADA
Tel: 1 (416) 486-9698, Fax: 1 (416) 486-8107,
info@wbu.ngo

The World Blind Union has an international directory of organizations and programs for people with vision loss. Contact them to get the names and addresses of programs in your region.

HEARING LOSS

We have listed some producers of materials for people with hearing loss. Remember that sign language differs from place to place. Investigate and observe what works well in your region and what materials are offered there.

Helping Children Who Are Deaf: Family and community support for children who do not hear well.

D. David, D. Greenstein, and S. Niemann

Published by Hesperian Health Guides, see p. 642

Kid-Friendly Parenting with Deaf and Hard of Hearing Children

D. Medwid and D.C. Weston

Published by Gallaudet University Press, 1995, 373 pages. <https://gupress.gallaudet.edu/2872.html>

A good book on parenting children with hearing loss.

It teaches a fun, flexible method for building good relationships between parents and children.

ASL Dictionary Online

www.handspeak.com.

A dictionary of short video clips showing how to sign over 7,500 words in American Sign Language.

Diglo (formerly Harris Communications)

15155 Technology Dr., Eden Prairie, MN 55344 USA.

Tel: (800) 825-6758, Fax: (952) 906-1099 www.diglo.com

This store specializes in products and publications that deal with hearing loss. Popular children's books in sign language. Aids and equipment for people with hearing loss.

The S.E.E. (Signing Exact English) Center.

10443 Los Alamitos Blvd., Los Alamitos, CA 90720, USA.

Tel: (562) 430-1467, seecenter@seecenter.org,
www.seecenter.org

The S.E.E. Center offers resources and trainings for teaching and learning sign language.

World Federation of the Deaf

P.O. Box 65, FIN-00401, Helsinki FINLAND

info@wfdeaf.org, <https://wfdeaf.org>

WFD includes national organizations of people with hearing loss in 120 countries. WFD works for human rights and equal opportunity for people with hearing loss, and the right of people with hearing loss to use sign language to get education and information.

THERAPY, EXERCISES, AND POSITIONING***Home Program Instruction Sheets for Infants and Young Children.***

L. Jaeger

Published by Psychological Corp, 1999, 215 pages.
(out of print)

Excellent, well-illustrated book of instruction sheets for many exercises. It includes range of motion exercises. (Revised version of the first edition by Jaeger and Hewitt)

Pediatric Strengthening Program.

L. Stern and K. Steidle

Published by Therapy Skill Builders, 1998, 124 pages.
(out of print)

Many playful activities to increase the strength of children with disabilities or those who are recovering from surgery. Pages can be copied and given to families so they will remember how to do the exercises with their children.

A Manual of Basic Physiotherapy for the Use of Nurses in Rural Hospitals.

E.A. Hardinge and P.M.P. Wilson

Published by Tear Fund, UNITED KINGDOM. 1981, 162 pages. (out of print)

Basic, clearly presented, very useful for training rehabilitation workers.

Positioning the Client With Central Nervous System Deficits: The wheelchair and other adapted equipment. (2nd edition)

A.F. Bergen and C. Colangelo

Published by Valhalla Rehabilitation Publications, 1985, 237 pages (out of print)

Detailed, in-depth discussion of adaptive seating to meet the needs of individual children with cerebral palsy. Excellent illustrations. Language is fairly complex.

CHILD DEVELOPMENT AND DEVELOPMENTAL DELAY***Developmental Motor Activities for Therapy—Instruction sheets for children.***

C. Sheda and C. Small

Published by Communication Skill Builders, 1990.
(out of print)

Well-illustrated and organized activities to promote physical development and motor skills in children. Sheets can be reproduced and given to families.

Special Education for Mentally Handicapped Pupils—A Teaching Manual. Revised Edition

C. Miles

Published by the Mental Health Centre, Peshawar, PAKISTAN. 1990, 283 pages.

Available free online:

www.files.eric.ed.gov/fulltext/ED361918.pdf

Excellent adaptation of special education to a resource-poor setting. Clearly written. A few good illustrations. Perhaps the best special education text for community programs.

National Down Syndrome Congress

30 Mansell Court, Suite 108, Roswell, GA 30076, USA.

Tel: (800) 232-6372, Fax: (770) 604-9898,

info@ndscenter.org, www.ndscenter.org

An organization that provides many small pamphlets on different issues concerning Down syndrome. They also offer a reading list for families.

BEHAVIOR TRAINING AND TOILET TRAINING***Listening to Children.***

P. Wipfler

Published by Hand in Hand Parenting, 2006

www.handinhandparenting.org

A series of 6 booklets that cover crying, fear, anger, special time, tantrums, and listening. A very new and revolutionary approach for dealing with feelings and behavior. Not written specifically for children with disabilities but the basic ideas work for everyone.

Toilet Training in Less Than a Day.

N. Azrin and R. Foxx

Published by Simon & Schuster, 2019, 192 pages.

simonandschuster.com

Good instructions for "the fast method"; oriented towards the USA and Europe.

TOYS AND GAMES***Extraordinary Play with Ordinary Things.***

B. Sher

Published by Writeart, 2006, 324 pages.

Play activities and games for children with varied levels of disability. Designed to encourage thinking, movement, coordination and balance. It uses materials and objects available in most homes.

Shared Moments: Learning Games for Disabled Children.

S.M. Rogow and J.L. Hass

Published by Tudor Publishers, 1993,

64 pages.

Learning games and activities designed to stimulate and encourage babies and children with physical, visual and developmental disabilities.

National Institute of Art and Disabilities

551 23rd Street, Richmond, CA 94804, USA.

Tel: (510) 620-0290, admin@niadart.org, www.niadart.org

An art center for people with disabilities. Website shows materials, equipment, aids, and instruction needed for many crafts and art forms.



AWARENESS RAISING; POLITICS OF DISABILITY, REHABILITATION, AND MEDICINE

The Acorn People.

R. Jones

Published by Laurel-Leaf Books, 1976, 80 pages
1745 Broadway, 10th Floor, New York, NY 10019 USA

A good, very human story about children with disabilities and their need for freedom, adventure, and understanding.

Louis Braille: The Boy Who Invented Books for the Blind.

M. Davidson

Published by Scholastic Book
Services
557 Broadway, New York, NY
10012 USA.

Excellent story for children about the accomplishments of a child with disabilities. Good reading for CHILD-to-child activities.



The Ragged Edge (formerly *The Disability Rag & Resource*) and *Advocado Press*
PO Box 406781, Louisville, KY 40204, USA
145@avocadopress.org, www.avocadopress.org.
www.raggededgemagazine.com

The Ragged Edge Magazine, a magazine by people with disabilities, is no longer being published, but all its good articles and analysis are available to read online. The publisher, Advocado Press, also publishes excellent books on disability.

AIDS, APPLIANCES, AND EQUIPMENT, INCLUDING WHEELCHAIRS

How to Make Basic Hospital Equipment

Compiled by R. England

Published by Intermediate Technology Publications Ltd.,
1979, 88 pages.

Available free online: http://frankshospitalworkshop.com/organisation/biomed_documents/How%20To%20Make%20Basic%20Hospital%20Equipment%20-%20Intermediate%20Technology.pdf

Simple tube metal wheelchairs and other designs from Africa. Well-illustrated and with useful comments. Fairly simple language.

Making Health-Care Equipment: Ideas for Local Design and Production.

A. Platt and N. Carter

Published by Practical Action Publishing, 1990, 88 pages.

The Shumacher Centre for Technology and
Development, 27A Albert Street, Rugby, Warwickshire
CV21 2SG UNITED KINGDOM

Tel: 44 1926 634501,

publishinginfo@practicalaction.org.uk,

<http://developmentbookshop.com>

Gives designs and ideas for equipment that can be made locally in small workshops using alternative materials and fabrication methods.

More with Less: Aids for Disabled People for Daily Living.

Edited by G. van der Hulst, M. Velthuys, and G. de Haan
Published by Backhuys Publishers, 1990, 104 pages.

Simply written in English, French, and Spanish, with illustrations on every page. Very good ideas.

Independence Through Mobility: A Guide to the Manufacture of the ATI-Hotchkiss Wheelchair

R. Hotchkiss

Published by Whirlwind Wheelchair International,
2111 San Pablo Ave. Unit 2956, Berkeley 94702, USA.
Tel: (510) 239-3557, info@whirlwindwheelchair.org,
www.whirlwindwheelchair.org

Available free online at: web.mit.edu/sp.784/www/DOCUMENTS/Independence%20through%20Mobility%20-%20Entire%20Document.pdf

Complete instructions to make the "Whirlwind," a high-quality, low-cost steel wheelchair. For a list of books about various types of personal transport for people with disabilities see pages 604 to 606.

Pavlik Harness Fact Sheet

Published by Seattle Children's Hospital, 2020, 4 pages.

Available free online:

<https://www.seattlechildrens.org/pdf/PE409S.pdf>

A fact sheet for caregivers of babies using Pavlik Harnesses, including diagrams, instructions for putting on the harness, and general care. Information in English and Spanish.



ARTIFICIAL LIMBS

Mukti M.S.Dadha Foundation

No. 1, Station Road, Meenambakkam, Chennai 600027
INDIA.

Tel: 044 22333168, muktiindia@gmail.com,

www.muktiindia.org.

This group has found a way to make a good quality, low-cost, artificial leg called the Mukti Limb. They also provide free braces to people who have experienced paralysis due to polio.