

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.

It has been many years since *Disabled Village Children* was written. Since then, many of the books that we recommended have gone out of print. This means that they are not published anymore. For this reason, the list of references in this edition is somewhat different from the original. We still give credit to books and authors whose materials we used. Whenever possible, we still include the name and address of the organization or publisher who distributes the materials, so anybody who wishes to can write directly to them.

In some cases, we were not able to find the producers or distributors of some books and we decided to take them out of the list to save you time and effort. But you may be able to find some books online or used, so we have left their information listed.

In this new list, we also include organizations and associations that offer information and materials on different disabilities. The services and materials they offer vary from one to the other. Some of them send free materials but most charge some money for them. Write to 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 disabled people exist where you are. It may be easier to get appropriate information and materials locally.

DISABILITY AND REHABILITATION—GENERAL

Training in the Community for People with Disability. 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: <http://www.who.int/disabilities/publications/cbr/training/en/>

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.

Special Needs Project. 324 State Street, Suite H, Santa Barbara, CA 93101 USA. Tel: (800) 333-6867, Fax: (805) 962-5087, books@specialneeds.com, www.specialneeds.com

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

Maxwell, Watts Belser and David. *A Health Handbook for Women with Disabilities.* Hesperian Health Guides, 1919 Addison St., Berkeley, CA 94704. Tel: 510-845-1447, Fax: 510-845-9141, bookorders@hesperian.org, www.hesperian.org 416 pages

Suggestions for women with disabilities and their caregivers on health care, sexuality, childbirth and other topics concerning women's health.

Levine, Suzanne. *Volver a Vivir/Return to Life.* A photographic report on the villager-run rehabilitation project, Project PROJIMO, in Mexico. Hesperian Health Guides (see address above)

PRIMARY HEALTH CARE

Werner, David. *Where There Is No Doctor.* Hesperian Health Guides, 1919 Addison St., Berkeley, CA 94704. Tel: 510-845-1447, Fax: 510-845-9141, bookorders@hesperian.org, www.hesperian.org 506 pages.

Widely used handbook for village health workers and families on basic curative and preventive health care. Second edition, revised and expanded.

Burns, Lovich, Maxwell and Shapiro. *Where Women Have No Doctor.* Hesperian Health Guides (see address above), 600 pages.

Medical information combined with the ways poverty and discrimination affect women's health.

Werner, David and Bower, Bill. *Helping Health Workers Learn.* Hesperian Health Guides (see address above). 632 pages.

A 'people-centered' educational approach to health care.

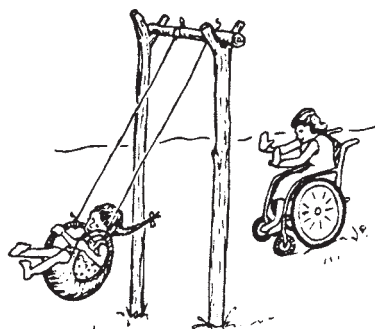
Dickson, Murray. *Where There Is No Dentist.* Hesperian Health Guides (see address above), 248 pages.

Basic information on care of teeth and gums.

POLIO

Huckstep, R.L. *Poliomyelitis: A Guide for Developing Countries—Including Appliances and Rehabilitation for the Disabled.* Available online: www.storage.googleapis.com/global-help-publications/books/help_poliomyelitis.pdf

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 (formerly *Polio Network News*). Post-Polio Health International, 4207 Lindell Blvd #110, St. Louis, MO 63108-2915, 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

Bower, Eva ed. Finnie's *Handling the Young Cerebral Palsied Child at Home*. Butterworth Heineman, 2008, 446 pages.

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.

Levitt, Sophie. *Treatment of Cerebral Palsy and Motor Delay*. Wiley-Blackwell Publications, 10475 Crosspoint Blvd. Indianapolis, IN 46256, USA. Fifth edition, 2010. Tel: (877) 762-2974, Fax: (800) 597-3299, www.wiley.com

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

MUSCULAR DYSTROPHY

Muscular Dystrophy Association, Inc. 222 S. Riverside Plaza, suite 1500, Chicago, IL 60606 USA. Tel: (800) 572-1717, www.mdausa.org, mda@mdausa.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, 6th fl., Atlanta, GA 30309 USA. Tel: (404) 872-7100, 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 of America (SBAA), 1600 Wilson Blvd., suite 800, Arlington, VA 22209 USA. Tel: (800) 621-3141, Fax: (202) 944-3295, 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.



Also from SBAA, *Bowel Continence and Spina Bifida*, and other publications; write for a list of their materials.

SHINE: *Spina bifida, Hydrocephaly, Information Networking Equality*. 42 Park Road, Peterborough, PE1 2UQ, UNITED KINGDOM. Tel: Tel: (44 845) 450 7755, Fax: (44-173) 355-5985, helpline@asbah.org, www.asbah.org

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

SPINAL CORD INJURY

Bromley, Ida. *Tetraplegia and Paraplegia: A Guide for Physiotherapists*. Churchill Livingstone, Elsevier. www.elsevier.com 2006, 428 pages.

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.holister.com/~media/files/pdfs-for-download/continence-care/hol_ccbl_living_w_sci_us_907500-112.pdf
Spanish: www.holister.com/~media/files/pdfs-for-download/continence-care/viviendo-con-una-lesion-en-la-medula-espinal_907640-712.pdf



Usefull, 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

Freeman, John M., Vinig, Eileen P.G. and Pillas, Diana J. *Seizures and Epilepsy in Childhood—A Guide*. Johns Hopkins University Press, 2715 North Charles Street, Baltimore, MD 21218-4363, USA Third edition 2002, 432 pages. Tel: (410) 516-6900, Fax: (410) 516-6998

Clearly explains many aspects of epilepsy in children. A good resource for a child with epilepsy and his family. It can also be bought from the Epilepsy Foundation.

Epilepsy Foundation of America. 8301 Professional Place, Landover, MD 20785, USA. Tel for English speakers: (800) 332-1000; Tel for Spanish speakers: (866) 748-8008 www.epilepsyfoundation.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: The Teaching and Learning Materials Co-ordinator, ILEP, 234 Blythe Road, LONDON W14 0HJ, UNITED KINGDOM, Tel: (44-20) 7602-6925, Fax: (44-20) 7371-1621, books@ilep.org.uk www.ilep.org.uk These ILEP materials are available free online in English and French.

ILEP Learning Guide No 1. How to diagnose and treat leprosy. 2001.

A new, well-illustrated publication suitable for the wide range of health professionals who need to recognize and treat leprosy.

ILEP Learning Guide No 2. How to recognize and manage leprosy reactions. 2002.

A comprehensive guide to identifying and managing leprosy reactions; includes details of how to safely prescribe corticosteroids.

Training Guide (2011) and **Rehabilitation Guide** (1999).

Two books on how to set up programs to help people with the disease and to recover physically and economically.

Guidelines to Reduce Stigma (2011)

A 4-book series.

Triple Jeopardy (2015)

Discrimination facing women and girls with leprosy.

BLINDNESS

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

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

Niemann, Sandy and Jacob, Namita, **Helping Children Who Are Blind: Family and community support for children with vision problems.** Hesperian Health Guides (see address on p. 637). 2000, 192 pages.

The simple activities in this book can help parents, caregivers, teachers, health workers, rehabilitation workers and others help a child with vision problems develop all his or her capabilities. It also has sections containing innovative charts on child development and easy-to-make, low-cost learning toys.

Sandford-Smith, John. **Eye Diseases in Hot Climates.** Ulverscroft Foundation, the Green, Bradgate Rd., Anstey, Leicester LE7 7FU, UNITED KINGDOM Tel: (44) 0116 2361595, www.ulverscroft-foundation.org.uk/about/our-publications 164 pages.

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.

World Blind Union. CBC-ONCE, C/ La Coruna 18, Madrid 28020, SPAIN. info@wbuoffice.org, www.worldblindunion.org

ONCE (National Spanish Association of the Blind) is also the home base of the World Blind Union. They have an international directory of organizations and

programs for the blind. Write to them to get the names and addresses of programs in your region.

DEAFNESS

We have listed some producers of materials for deaf people. 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. Hesperian Health Guides (see address on p. 637). 2003, 250 pages.

This book has activities for helping deaf children communicate to the fullest of their ability, including learning a language. It helps parents make good decisions about the development of a child who is deaf.

Harris Communications, 15155 Technology Dr., Eden Prairie, MN 55344 USA. tel: (800) 825-6758. www.harriscomm.com

This store specializes in products and publications that deal with deafness. Popular children's books in sign language. Aids and equipment for deaf persons.

Medwid, Daria and Weston, Denise C. **Kid Friendly Parenting with Deaf and Hard of Hearing Children.** Gallaudet University Press. 800 Florida Avenue NE, Washington, DC 20002-3695, USA. Tel: (202) 651-5488

A good book on parenting deaf children. It teaches a fun, flexible method for building good relationships between parents and children.

The SEE (Signing Exact English) Center. 10443 Los Alamitos Blvd., Los Alamitos, CA 90720, USA. 1993, 479 pages. Tel: (562) 430-1467, seecenter@seecenter.org, www.seecenter.org

Signing Exact English offers resources and trainings for teaching and learning sign language.

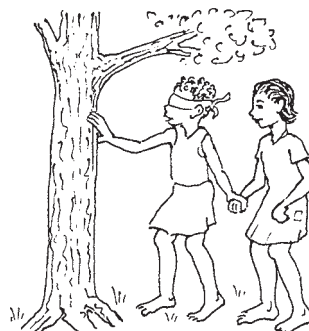
ASL Dictionary Online www.handspeak.com.

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

THERAPY, EXERCISES, AND POSITIONING

Hardinge, Elizabeth A., and Wilson, Patricia M.P. **A Manual of Basic Physiotherapy for the Use of Nurses in Rural Hospitals.** Tear Fund, UNITED KINGDOM. 1981, 162 pages. (out of print)

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



Bergen, Adrienne Falk and Colangelo, Cheryl. *Positioning the Client With Central Nervous System Deficits: The wheelchair and other adapted equipment*. Valhalla Rehabilitation Publications, 1985 (second edition), 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.

Jaeger, D. LaVonne. *Home Program Instruction Sheets for Infants and Young Children*. PsychCorps division of Pearson, PO Box 599700, San Antonio, TX 78259 USA. (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.)

Stern, Linda and Steidle, Kathryn. *Pediatric Strengthening Program*. PsychCorps (see reference above). (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.

Physical Therapy Assistant's Manual. Handicap International. Sectur Ventas, 14 Av. Berthelot, 69361 Lyon, Cedex 07, FRANCE. (out of print)

Three volumes of 170 pages each. Simple manuals that teach how to provide physical therapy. The first book covers theory and basic anatomy. The second book shows therapy techniques. And the third one helps you choose an exercise program according to the particular disability. Good illustrations and clearly written.

CHILD DEVELOPMENT AND DEVELOPMENTAL DELAY

Miles, Christine. *Special Education for Mentally Handicapped Children—A Teaching Manual*. Mental Health Centre, Dabgari Gardens, Peshawar Cantt., North West Frontier Province, PAKISTAN. Revised edition, 1990, 277 pages. Email inquiries to: Humphrey Peters: humphrey@brain.net.pk Available online: www.files.eric.ed.gov/fulltext/ED361918.pdf

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

Sheda, Constance and Small, Christine. *Developmental Motor Activities for Therapy—Instruction sheets for children*. Therapy Skill Builders (see address above).

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

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

Wipfler, Patty. *Listening to Children*. Hand in Hand, 55 Waverly St. Suite 25, Palo Alto, CA 94301, USA. Tel: (650) 322-5323, 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 disabled children but the basic ideas work for everyone.

Azrin, Nathan and Foxx, Richard. *Toilet Training in Less Than a Day*. Simon & Schuster, skimonandschuster.com, 1989, 176 pages.

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

TOYS AND GAMES

National Institute of Art and Disabilities, 551 23rd Street, Richmond, CA 94804, USA. 1983, 235 pages. Tel: (510) 620-0290, admin@niadart.org, www.niadart.org

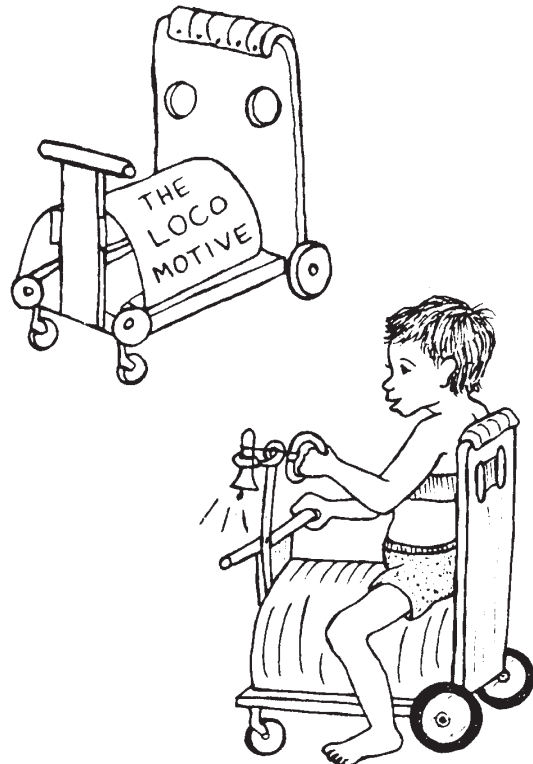
An art center for disabled people. Website shows materials, equipment, aids, and instruction needed for many crafts and art forms.

Sher, Barbara. *Extraordinary Play with Ordinary Things*.

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.

Rogow, Sally M. *Shared Moments: Learning Games for Disabled Children*.

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



AWARENESS RAISING; POLITICS OF DISABILITY, REHABILITATION, AND MEDICINE

Jones, Ron. *The Acorn People*. Laurel-Leaf Books, 1745 Broadway, 10th Floor, New York, NY 10019 USA 1976, 80 pages.

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

Davidson, Margaret. *Louis Braille: The Boy Who Invented Books for the Blind*. Scholastic Book Services, 557 Broadway, New York, NY 10012 USA.

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

The Ragged Edge (formerly *The Disability Rag & Resource*) and **Avocado Press**
PO Box 406781, Louisville, KY 40204, USA. contact145@avocadopress.org, www.avocadopress.org

The Ragged Edge Magazine by disabled people is no longer being published, but all its good articles and analysis are available to read online at www.raggededgemagazine.com
It's publisher, Avacado Press, also publishes excellent books on disability.

Disability Awareness in Action. info@daa.org.uk, www.daa.org

This organization maintains a website dedicated to fostering the integration of disabled people and advocating respect for their rights. Excellent materials on how to organize and maintain an organization of disabled people.

AIDS, APPLIANCES, AND SPECIAL EQUIPMENT, INCLUDING WHEELCHAIRS

How to Make Basic Hospital Equipment, compiled by Roger England. Practical Action Publishing, The Shumacher Centre for Technology and Development, Bourton on Dunsmore, Rugby, Warwickshire CV23 9QZ UNITED KINGDOM. 1979, 88 pages. Tel: 44 1926 634501, publishinginfo@practicalaction.org.uk, <http://developmentbookshop.com>

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

UPKARAN: A Manual of Aids For the Multiply Handicapped. Bandra Reclamation, K.C. Marg, Bandra (West), Mumbai 400 050, INDIA. Tel: 91 2644 3666, drmithualur@nrcissi.org, www.nrcissi.org

Many excellent and mostly simple aids, well illustrated. Written in English and Hindi.

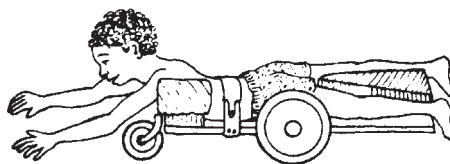
More with Less: Aids for Disabled People for Daily Living. TOOL Publications, PO Box 321, 2300 AH Leiden, THE NETHERLANDS. (out of print)

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

Hotchkiss, Ralf. *Independence Through Mobility: A Guide to the Manufacture of the ATI-Hotchkiss*

Wheelchair. Whirlwind Wheelchair International, 2703 7th St., suite 134, Berkeley, CA 94710, USA. Tel: (510) 204-9333, info@whirlwindwheelchair.org, www.whirlwindwheelchair.org Available free online at: www.web.unit.edu/sp.784/www/DOCUMENT/Independence%20through%20mobility%20-%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 disabled people see pages 604 to 606.



ARTIFICIAL LIMBS

Simple Below-knee Prosthesis Manufacture and Simple Above-knee Prosthesis Manufacture. Dartnell. Handicap International (see address on p. 640). (out of print)

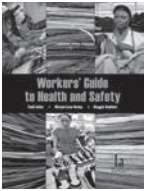
Excellent. Fairly simple methods for making prostheses. See page 634 for a brief overview.



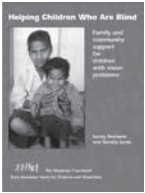
Other books from the Hesperian Foundation



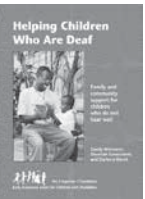
A Health Handbook for Women with Disabilities by Jane Maxwell, Julia Watts Belser and Darlena David provides women with disabilities and their caregivers advice on disability-friendly health care, caring for daily needs, healthy and safe sexual relationships, family planning, pregnancy and childbirth, and defense against violence and abuse. The book focuses on physical issues as well as social stigma and discrimination. 406 pages.



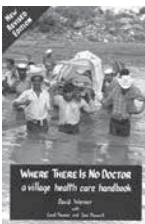
Workers' Guide to Health and Safety, by Todd Jailer, Miriam Lara-Meloy and Maggie Robbins, makes occupational safety and health accessible to those most affected by hazards — the workers themselves. An invaluable resource for training workers, supervisors, and safety committees, and in courses on labor relations. 576 pages.



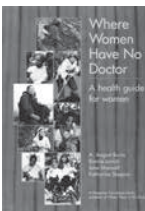
Helping Children Who Are Blind, by Sandy Niemann and Namita Jacob, aids parents and caregivers to help blind children from birth through age 5 develop all their capabilities. Includes: assessing how much a child can see, preventing blindness, moving safely, teaching common activities, and others. 192 pages.



Helping Children Who Are Deaf, by Darlena David, Devorah Greenstein and Sandy Niemann, aids parents, teachers, and caregivers help deaf children learn basic communication skills and language. It gives simple methods to assess hearing loss, develop listening skills, explores how communities can help deaf children, and ways parents and caregivers can support each other. 250 pages.



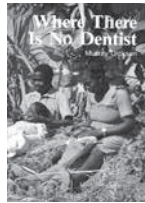
Where There Is No Doctor, by David Werner with Carol Thuman and Jane Maxwell. The most widely used health care manual in the world provides easy to understand information on how to diagnose, treat and prevent common diseases, emphasizing prevention: cleanliness, diet, vaccinations and community mobilization. 512 pages.



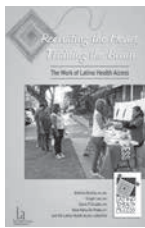
Where Women Have No Doctor, by A. August Burns, Ronnie Lovich, Jane Maxwell and Katharine Shapiro, combines self-help medical information with an understanding of the social factors that limit women's health. Essential information on problems that affect only women or affect women differently from men. 584 pages.



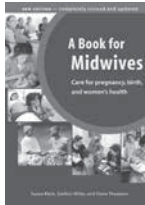
Health Actions for Women, by Melissa Smith, Sarah Shannon and Kathleen Vickery. Field tested by 41 community groups in 23 countries, it provides a wealth of clearly explained and engagingly illustrated activities, strategies and stories addressing the obstacles and practices that prevent women and girls from enjoying healthy lives. 352 pages.



Where There Is No Dentist, by Murray Dickson. How to care for teeth and gums at home, and in community and school settings. Detailed and illustrated information on dental equipment, placing fillings and pulling teeth, teaching hygiene and nutrition, and HIV and oral health. 208 pages



Recruiting the Heart, Training the Brain tells the story of Latino Health Access' groundbreaking promotor model of peer-to-peer outreach and education in Santa Ana, California. Facing problems such as obesity and diabetes, poverty and discrimination, their advice and accomplishments will spark hope and change across an increasingly unhealthy country. 288 pages.



A Book for Midwives, by Susan Klein, Suellen Miller and Fiona Thomson, a training tool and reference for anyone concerned about the health of women and babies in pregnancy, birth and beyond. Prenatal care, labor & delivery, complications, breastfeeding, and reproductive health. 544 pages.



A Community Guide to Environmental Health, by Jeff Conant and Pam Fadem, helps urban and rural health promoters, activists and community leaders take charge of their environmental health. From toilets to toxics, watershed management to waste management, and agriculture to air pollution. Activities, how-to make health technologies, and dozens of stories. 600 pages.



Helping Health Workers Learn, by David Werner and Bill Bower, is an indispensable resource that shows how to make health education fun and effective. Includes activities, tips, and techniques, and ideas for low-cost teaching aids. Emphasizing a people-centered approach to health care, it presents strategies for effective community involvement through participatory education. 640 pages.

All titles are available from Hesperian in both English and Spanish. For information regarding other language editions, prices and ordering information, or a description of Hesperian's work, please visit our website or write to us.



Hesperian Health Guides
1919 Addison St., #304
Berkeley, California 94704 USA
tel: (510) 845-4507, fax: (510) 845-0539
email: bookorders@hesperian.org
Visit our website: www.hesperian.org