



Nursing care resources for individuals with intellectual and developmental disabilities across the life span

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The resources encourage individuals with intellectual and developmental disabilities (I/DD), along with their parents/families or caregivers to learn about a range of topics including advocacy issues, assistive technology (AT), communication, health care access, disability history and culture, health promotion, and disability related legislation. Additionally, age-specific resources are included to address particular needs of infants and young children, adolescents, and older persons. Lastly, resources related to professional associations and organizations that advocate and disseminate research findings for individuals with I/DD and their caregivers across the life span are provided.

Advocacy across the life span

Advocating Change Together (ACT). ACT is a nonprofit disability rights organization committed to freedom, equality, and justice for all people with disabilities; and run by and for people with developmental and other disabilities. ACT develops programs that educate people about the self-advocacy movement and promote personal and group empowerment. The

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curriculum concept was developed in response to the growing concern that individuals with disabilities were being isolated and excluded from decisions regarding their lives. In 1996, ACT began developing a video-based curriculum series to meet these needs. Tools for Change is a participatory and accessible education program for people of all abilities. <http://www.selfadvocacy.com/>.

A Credo for Support. N. Kunc & E. Van der Klift (1996). A Credo for Support is a powerful 5-minute video that offers a series of suggestions for people who care about and support someone with a disability. The video prompts viewers to question the common perceptions of disability, professionalism, and support. Designed for use in presentations, in-service, staff training, and orientation programs, to be a provocative catalyst for a dialogue on these issues. <http://www.normemma.com/>.

Axis Consultation and Training, Ltd. N. Kunc and E. Van der Klift's consulting firm that provides in-service and consultation in the areas of advocacy, inclusive education, employment equity, conflict resolution, and management in human services. This website provide a number of advocacy articles written by Kunc and Van der Klift. <http://www.normemma.com/indxarti.htm>.

Making Choices As We Age: A Peer Training Program. T. Heller, L. Preston, T. Nelis, A. Brown, E. and Pederson (1996). This is a curriculum for training persons with disabilities and for their cotrainers in how to teach other adults with mental retardation about: healthy choice making, rights and responsibilities, and things to do in their free time. The Trainer's Guide uses a "train-the-trainer" approach so the persons with disabilities who are trainers and their cotrainers can learn how to teach effectively and how to administer each module. The Coordinator's Guide provides guidelines for administering the training program and for building support for peer trainers and the other participants who they, in turn, train. Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities, The University of Illinois at Chicago. Item No. 100.004—<http://www.uic.edu/orgs/rrtcaml/>.

People First. People First networks with other states and advocacy groups. People with developmental disabilities joining together to learn how to speak for themselves. Disabled people form chapters at their work places or where they live, including institutions, foster homes, their parents' homes, group homes, and their own apartments. There are local chapters and state chapters. A directory of People First organizations was prepared by Arc (www.thearc.org) and can be found at http://www.open.org/~people1/articles/self_advocacy_directory.htm.

Self Advocates Becoming Empowered (SABE). Self-advocates with goals of making self-advocacy available in every state including institutions, high schools, and rural areas; people with families with local support and advisors to help; people with disabilities about their rights within the criminal justice system; closing institutions for people with developmental

disabilities; labels nationwide; and building community supports. <http://www.sabeusa.org/>.

The Association for Persons with Severe Handicaps (TASH). This is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm. <http://www.tash.org/>.

The Rights Stuff: Self Advocates Learning and Using Their Rights. W. Hollo (2000). This book and video set is a tool for teaching staff and self-advocates regarding rights, and it demonstrates how agencies can develop and use a bill of rights written by those who receive service. The book presents a step-by-step process that agencies can follow to help individuals within their care learn about rights and responsibilities. Included is the groundbreaking “bill of rights” written by self-advocates. <http://www.diverse-city.com/display.htm>.

Assistive technology

Assistive Technology and You: A Guide for Families and Persons with Disabilities. G. Hedman, K. Hooyenga, P. Politano, and B. Sposato (1997). This guidebook provides information about the various uses of AT for accessibility, activities of daily living, augmentative communication, computer access, environmental control, seating, mobility, and work-site modification. This booklet contains photographs and descriptions of devices, and their applications, and guidelines to help families and users become informed consumers in selecting equipment. The guide was written by AT clinicians and reviewed by consumers, families, and community agency professionals. It was developed by the AT Unit at the Institute on Disability and Human Development in collaboration with the RRTC on Aging with Developmental Disabilities. Item No. 700.002—<http://www.uic.edu/orgs/rrtcamlr/jan02pubslist.htm>.

Closing the Gap: Computer Technology in Special Education and Rehabilitation. V. Zarach (2000). Provides practical up-to-date information on AT products, procedures, and best practices. <http://www.closingthegap.com/>.

Outcomes of AT Services and Use by Adults with Developmental Disabilities. J. Hammel, T. Heller, and G. Ying (1998). Rehabilitation Engineering and AT Society of North America (RESNA) 1998 Annual Conference Proceedings, p.14–16. A report of an outcome study of AT service delivery, use, and relationship to functional status changes over time. The study was conducted among adults specifically with cerebral palsy and mental retardation living in the community. Item No. 700.003—<http://www.uic.edu/orgs/rrtcamlr/jan02pubslist.htm>.

RehabCentral.com. Provides resources to find rehabilitation products and assistive devices. <http://www.rehabcentral.com/>.

Rehabilitation Engineering and AT Society of North America. An interdisciplinary association of people interested in technology and disability to improve the potential of people with disabilities to achieve their goals through the use of technology. <http://www.resna.org/resna/>.

Using Assistive Technology to Maximize Function in Older Adults with Developmental Disabilities. T. Alvarez, M. Desi-Thalji, J. Wang, S. Budraja, V. Sundar, and C. Malik (2002). This training curriculum provides information and resources on how AT and environmental interventions (EI) can address age-related changes in function for older adults with developmental disabilities in the everyday contexts of the home, workplace, and community. The modules cover: basic AT-EI products and terminologies; seating, positioning, and mobility; sensory issues; gross and fine motor functioning; communication, cognition and learning; and the AT-EI delivery process and funding. The training package contains a scripted instructor's guide and seven training modules with power point slides. It was designed for professionals, paraprofessionals, and families, and the content can be tailored to a 2-hour workshop or to multiple sessions. Item No. 700.006—<http://www.uic.edu/orgs/rrtcamr/jan02pubslist.htm>.

Communication and access issues in health-care settings

Accessibility of Primary Care Physicians' Offices for People with Disabilities. E. Grabois, M. Nosek, and C. Rossi (1999). An analysis of compliance with the Americans with Disabilities Act. *Archives of Family Medicine* (1999);8(1):44–51.

A Strategy to Train Health Care Professionals to Communicate with Adults with Mental Retardation. J.L. Harper, D. Harper, et al (1990). A 19-minute video to train health-care professionals to communicate with adults. To request this resource from the Disability Resource Library: Item #: 402990, E-mail: disability-library@uiowa.edu, Phone: 877-272-7713 (toll-free, voice), 877-686-0032 (toll-free, TTY), 319-356-1345, Mail: UHS Disability Resource Library, 311 HS, 100 Hawkins Drive, Iowa City, IA 52242-1011. <http://www.medicine.uiowa.edu/uhs/DRL/>.

Be a Savvy Health Care Consumer, Your Life May Depend on It. J.I. Kailes (1998). Excellent resource providing information on seeking and receiving proper medical care and keeping your own medical records. Provides disability-specific strategies and examples. Helpful checklists include: Visit Strategies; Outline for Information Giving; Procedures, Tests and Consultations; Medication; What to Look for in Health Care Providers; and Hospitals: Be Assertive about Your Needs. Provides suggestions for what to take while traveling and an Emergency Health Information form. Recommended for anyone who interacts with health-care providers or is an advocate. For more information about this guide, contact the author at

jik@pacbell.net or write to KAILES Publications, 6201 Ocean Front Walk/Suite 2, Playa del Rey, CA 90293. <http://www.jik.com>.

Communicating Comfortably with a Person Who Is Visually Impaired. American Foundation for the Blind (AFB) (1998). A guide to communication with individuals who are blind or visually disabled. <http://www.afb.org/>.

Health Care Treatment Decision-Making Guidelines for Adults With Developmental Disabilities. Midwest Bioethics Center and University of Missouri-Kansas City Institute for Human Development Task Force on Health Care for Adults with Developmental Disabilities. Guidelines document using health-care decision-making model, with discussion of key terms, concepts, definitions, and ethical principles of decision-making. Available from: Midwest Bioethics Center, 1100 Pennsylvania Avenue/Suite 4041, Kansas City, MO 64105, 816-221-1100; fax: 816/221-2002; e-mail: midwestio@aol.com. <http://www.midbio.org/>.

Nursing Care Guidelines: Head to Toe Forms, Health Care Protocol for Use with Persons with Developmental Disabilities; and Passport Profile. D. Perry, and D.E. Lewis (1999). A set of materials and forms for nurses to use in training staff and caregivers to observe individuals for changes that may indicate a change in health status, identify action needed when a health issue occurs, and document an individual's health and functional status for health-care visits. M.A. Lewis, Regents, University of California. Contact: Dr. Mary Ann Lewis, University of California School of Nursing, Box 956919, Los Angeles, CA 90095-6919.

Removing Barriers: Tips and Strategies to Promote Accessible Communication. The North Carolina Office on Disability and Health (1999). A guide that addresses the basics on ways to communicate effectively and interact with people with disabilities. <http://www.fpg.unc.edu/~ncodh/removingbarriers/removingbarrierspubs.htm>.

Talking with Your Doctor: A Guide for Older People. NIH Publication # 94-3452 (2002). A guide for older persons on choosing a doctor, tips for good communication, beginning with a new provider, talking about your health, discussing sensitive subjects, involving friends and family, and resources. Call 1-800-222-2225 or <http://www.nia.nih.gov/health/pubs/talking/>.

The Ten Commandments of Communicating with People with Disabilities. I.M. Ward (1994). A 26-minute video that can be used in a wide variety of settings to increase sensitivity and awareness of appropriate language and behavior when communicating with people who have a disability of any kind. To request this resource from the Disability Resource Library: Item #: 211970.0, E-mail: disability-library@uiowa.edu, Phone: 877-272-7713 (toll-free, voice), 877-686-0032 (toll-free, TTY), 319-356-1345, Mail: UHS Disability Resource Library, 311 HS, 100 Hawkins Drive, Iowa City, IA 52242-1011. <http://www.medicine.uiowa.edu/uhs/DRL/>.

Disability history/culture

Deaf in America; Voices from a Culture. C. Padden and T. Humphries (1988). Harvard University Press: Boston. This book discusses how deaf culture works, what it means to its members, how they define themselves within it, and how they interact with the world outside.

Disability Culture Rap. *Advocating Change Together (ACT)* (2001). An award-winning documentary examining what it means to be disabled in America, featuring Cheryl Marie Wade. Through hundreds of images and a high-energy delivery, the film presents disability pride, independent living, the power of language and images, sexuality, community, and the right to live with dignity. 1821 University Avenue/Suite 306-S, St. Paul, MN 55104, 800 641-0059, <http://www.selfadvocacy.com>.

Disability History Project: Beyond Affliction. L. Block (1998). A 4-hour documentary radio series about the shared experience of people with disabilities and their families since the beginning of the nineteenth century. This Web site includes excerpts from the shows, as well as many of the primary source documents—extended interviews, images, and texts—from which the on-air programs were developed. Retrieved July 34, 2002, from the World Wide Web: <http://www.npr.org/programs/disability/index.html>.

No Pity: People with Disabilities Forging a New Civil Rights Movement. J.P. Shapiro (1993). An excellent resource about the social and political barriers and the disability rights movement. Random House, Inc.: New York.

Self-Advocacy: Freedom, Equality, and Justice for All. *Advocating Change Together (ACT)* (1996). An award-winning educational documentary (U.S. International Film & Video Festival, and Columbus International Film & Video Festival) illustrating the origins and meanings of the self-advocacy movement, a civil and human rights movement by persons with developmental disabilities. 1821 University Avenue/Suite 306-S, St. Paul, MN 55104, 800 641-0059, <http://www.selfadvocacy.com>.

The Raged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag. B. Shaw, editor. The Advocado Press: Louisville, KY;1994.

Issues across the life span for individuals with I/DD

Family Village Community Health Care Center. Resources for medical, health, transportation, therapeutic, and supportive resources, including cooking and nutrition, health-care advocacy and financing, long-term care, supports for seriously ill children and their families, and dental information. <http://www.familyvillage.wisc.edu/hospital.htm>

International Classification of Functioning (ICF), Disability and Health. World Health Organization (WHO). ICF classifies health and health-related domains that describe body functions and structures, activities, and participation, and describes how people live with their health condition. <http://www3.who.int/icf/icftemplate.cfm>.

National Center for the Dissemination of Disability Research (NCDDR). NCDDR was established in 1995 to conduct activities in the areas of: research activities, demonstration activities, dissemination and utilization activities, and technical assistance. <http://www.ncddr.org/>.

The National Down Syndrome Society (NDSS). NDSS was established in 1979 to ensure that all people with Down syndrome have the opportunity to achieve their full potential in community life. Currently, NDSS is the largest nongovernmental supporter of Down syndrome research in the United States and continues to increase public awareness about Down syndrome and discover its underlying causes through research, education, and advocacy. <http://www.ndss.org/>.

Nursing Care of the Individual with Down Syndrome: A Life Span Approach. HealthSoft, Inc. (2002). This courseware introduces nurses to the care of individuals with Down syndrome in a variety of practice settings. <http://www.nursingresourcecenter.com/>.

Promoting Health in Adults with Down Syndrome. B. Chicoine and D. McGuire (1996). This paper addresses health and psychosocial issues for adults with Down syndrome. It is based on the authors' clinical experience with more than 500 people at the Adult Down Syndrome Clinic based at a suburban Chicago hospital. Issues of lifestyle, screening and evaluation, immunization, mental health, and health education are discussed. RRTC on Aging with Developmental Disabilities, The University of Illinois at Chicago. Item No. 520.005 - <http://www.uic.edu/orgs/rrtcaml/>.

Removing Barriers to Health Care: A Guide for Health Professionals. The Center for Universal Design and The North Carolina Office on Disability and Health (1998). This document provides guidelines and recommendations to help health-care professionals make a medical facility physically accessible and ensure equal use of the facility and services by all their patients. <http://www.fpg.unc.edu/~ncodh/Communicate.html>.

Infants and young children with I/DD

Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents: Pocket Guide, 2nd edition. M. Green, J.S. Palfrey, E.M. Clark, J.M. Anastasi, editors (2001). Sponsored by Maternal and Child Health Bureau Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services. Arlington, VA: National Center for Education in Maternal and Child Health. <http://www.brightfutures.org>.

Developmentally Supportive Care and Early Intervention. National Early Childhood Technical Assistance System (NECTAS) web site will provide these sites. NECTAS supports the national implementation of the early childhood provisions of the Individuals with Disabilities Education Act. Its mission is “to strengthen systems at all levels to ensure that children (birth through five) with disabilities and their families receive and benefit

from high quality, culturally appropriate and family centered supports and services.” The NECTAS Contact List, Part C Programs, lists state contacts by telephone, e-mail, and some web sites. Some states divide the program by counties and others by regions. <http://www.nectac.org/txtdefault.asp>.

In: *Difference—A Little Book about Diversity*. M. Soucie, A. Milberg, and D. Hingsburger. Astra Milberg is a woman with Down syndrome who has a powerful voice; her article, “Letter to a Baby” has inspired thousands of people. This article has been described as “powerful,” “inspiring,” and “challenging.” <http://www.diverse-city.com/display.htm>.

With Open Arms: Embracing a Bright Financial Future for You and Your Child with Disabilities and Other Special Needs. New Financial Guide for Parents of Children with Disabilities and Other Special Needs, Easter Seals and the National Endowment for Financial Education® (NEFE®) have collaborated to create a 72-page financial-planning booklet for parents, caregivers, grandparents, and others involved in the care of a special needs child. Included is information on estate planning, finding the right lawyer or knowledgeable financial planner, wills, special-needs trusts, government benefits, savings options, insurance plans, and other available resources. Easter Seals and NEFE encourage families to start financial planning when their child with a disability is at a young age. Easter Seals National Headquarters, 230 West Monroe/Suite 1800, Chicago, IL 60606; toll-free phone: 800 221-6827, <http://www.easter-seals.org/resources/openarms.asp>.

Adolescents and adults with I/DD and family issues

Developmental Disabilities Center. The J.P. Das Developmental Disabilities Center web site from the University of Alberta in Edmonton, Canada, provides information on a range of topics related to developmental disabilities, including from the heart, poems and stories for parents, health, education, keeping your child safe, family life experiences, hope and transformation in families, considering siblings, just for fun, and some links for parents. Information on ICAD-L, on abuse and violence in the lives of people with developmental disabilities, is also available on this site. <http://www.quasar.ualberta.ca/ddc/development/index.html>.

IASSID: Health Guidelines for Adults with an Intellectual Disability. <http://www.iassid.org/pdf/healthguidelines.pdf>.

The Question of David: A Disabled Mother’s Journey Through Adoption, Family, and Life. D.S. Jacobson (1999). Berkeley, CA: Creative Arts Book Company;1999.

Through the Looking Glass (TLG). TLG is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent, or grandparent has a disability or medical issue. TLG was founded in 1982 in Berkeley, California. With a mission to create, demonstrate, and encourage nonpathologic and empowering resources and model early intervention services for families with disability issues in a parent

or child that integrate expertise derived from personal disability experience and disability culture. <http://www.lookingglass.org/>.

Aging issues and older adults with I/DD

Aging family caregivers: Needs and policy concerns. T. Heller (2000). This policy brief discusses the needs of aging caregivers, including planning for the future of their relative with a developmental disability. It addresses cultural differences in family caregiving and trends in family support policies. RRTC on Aging with Developmental Disabilities, The University of Illinois at Chicago. Item No. 310.013 - <http://www.uic.edu/orgs/rrtcamr/>.

Aging and Developmental Disabilities—An In-service Curriculum (2nd edition). R.H. Macheimer, Jr., editor (1997). The curriculum discusses aging, developmental disabilities, service systems, family/caregiving, aging with cerebral palsy, aging with Down syndrome, and environmental design. Rochester, NY: University of Rochester;1997. <http://www.urmc.rochester.edu/strong/SCDD/TPADD/order.htm>.

Aging and Intellectual Disabilities: Improving Longevity and Promoting Healthy Aging. Aging and Intellectual Disabilities Special Interest Research Group (SIRG) of The International Association for the Scientific Study of Intellectual Disability (IASSID). Documents jointly prepared by IASSID and Inclusion International (II) in collaboration with the Department of Mental Health and Substance Dependence and The Program on Aging and Health, World Health Organization, Geneva. Five reports include: Healthy Aging—Adults with Intellectual Disabilities Summative Report: Aging and Social Policy; Physical Health Issues; Women’s Health and Related Issues; and Biobehavioral Issues. <http://www.uic.edu/orgs/rrtcamr/jan02pubslist.htm>, or http://www.who.int/mental_health or www.waisman.wisc.edu/IASSID/SIRGAID.

Aging Issues: Administration on Aging. This site has many references relating to aging issues. <http://www.aoa.dhhs.gov/aoa/pages/agepages/aids.html>

Aging-Related Changes in Adults with Mental Retardation: Final Report. B.A. Hawkins and S.J. Eklund (1994). This 4-year longitudinal study examines the impact of aging on the physical, cognitive, adaptive, and social functioning of two distinct groups of adults with mental retardation: individuals with and without Down syndrome. It is a follow-up to the report of the first 3 years of study, *Detecting Aging-Related Declines in Adults with Developmental Disabilities*: <http://www.uic.edu/orgs/rrtcamr/>.

Aging with Developmental Disabilities: Changes in Vision. M.E. Flax and C. Luchterhand (1996). This fact sheet provides answers to the following questions: What are the typical changes in vision as people age? How will vision loss affect the adult with developmental disabilities? What can be done to make the best of the vision someone has? What information

is helpful to bring to an eye-care specialist? What should you ask at the eye exam? Where can a person get additional information and assistance regarding vision problems? <http://www.uic.edu/orgs/rrtcamr/>.

Aging, Mental Retardation and Physical Fitness. J. Rimmer (1997). This fact sheet provides an overview of what physical fitness is and how it relates to older people with mental retardation. It includes helpful guidelines for family members, support people, service providers, and others interested in starting a program for older individuals with mental retardation. <http://www.uic.edu/orgs/rrtcamr/>.

Aging with Mental Retardation: Oral Health for Older Individuals with Disabilities (2001). P. Farsai and J. Calabrese. This fact sheet discusses oral health care for older people with disabilities. It explains the conditions leading to oral health problems for people with disabilities and specifies what to look for in dental treatment and in choosing a dentist. The fact sheet also discusses barriers to accessing proper oral health care and provides recommendations for maintaining proper oral hygiene as people with disabilities age. <http://www.uic.edu/orgs/rrtcamr/>.

Dementia, Aging, and Intellectual Disabilities: A Handbook. M.P. Janicki and A.J. Dalton (1998). This text examines the impact of Alzheimer's disease and other dementias on people with mental retardation from an applied and practical perspective. It provides an up-to-date review of current knowledge on the diagnosis, assessment, treatment, care management, and care practices of dementias for people with mental retardation. RRTC on Aging with Developmental Disabilities, The University of Illinois at Chicago. <http://www.uic.edu/orgs/rrtcamr/>.

End-of-Life Care: A Guide for Supporting Older People with Intellectual Disabilities and their Families. NYSARC. This monograph is a comprehensive manual on end-of-life care issues for people with developmental disabilities. <http://www.nysarc.org>.

Fact Sheets on Aging. American Association for Retired Persons. <http://www.aarp.org/health/>.

Growing Older with a Developmental Disability: Physical and Cognitive Changes and Their Implications. A. Factor. The Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago (UIC) Department of Disability and Human Development (University-Affiliated Programs, or UAP). <http://www.uic.edu/orgs/rrtcamr/>.

Hearing Changes in Aging People with Mental Retardation (1999). M. Bagley and J. Mascia. This fact sheet provides answers to frequently asked questions about age-related hearing loss, especially for people with developmental disabilities. It contains the information families and service providers need to identify possible hearing loss and to support older adults who have this condition. <http://www.uic.edu/orgs/rrtcamr/>.

Home Control Through Trust and Estate Planning. T.M. Varnet and R.C. Spain (1995). Chicago: Law Firm of Spain, Spain, and Varnet, P.C.

McCracken Intervention Matrix: Guidelines for Careers to Help Older Adults with Mental Retardation Maintain Optimal Functioning. A. McCracken and T. Lottman. Chicago: Rehabilitation Research and Training Center on Aging with Mental Retardation, University of Illinois at Chicago. <http://www.uic.edu/orgs/rrtcamr/>.

Older Adults with Mental Retardation/Developmental Disabilities and Their Aging Family Caregivers. T. Heller and A. Factor (1999). This fact sheet uses a question-and-answer format to present frequently requested information about aging with mental retardation. It provides an overview of demographics, age-related changes, service, and support needs for older adults and their families, and new service models and resources. RRTC on Aging with Developmental Disabilities, The University of Illinois at Chicago. Item No. 600.001—<http://www.uic.edu/orgs/rrtcamr/>.

PCAD Project—Preparing Community Agencies for Adults Affected by Dementia. A project that establishes the best practices for the care of persons with developmental disabilities who develop dementia. <http://www.uic.edu/orgs/rrtcamr/pcad.htm>.

Person-Centered Planning for Later Life: A Curriculum for Adults with Mental Retardation. E. Sutton, T. Heller, H. Sterns, and S. Miklos (1993). This research-based curriculum enables adults with mental retardation to plan for their later years actively by teaching aging concepts and choice-making skills. The 20-week training, which includes a student notebook, provides classroom and community experiences for making choices regarding healthy aging, free-time activities, work and retirement, and improving living arrangements. RRTC on Aging with Developmental Disabilities, The University of Illinois at Chicago. Item No. 100.002—<http://www.uic.edu/orgs/rrtcamr/>.

Person-Centered Planning for Later Life: Death and Dying—A Curriculum for Adults with Mental Retardation. H. Sterns, E. Kennedy, and C. Sed. (2000). This training curriculum helps adults with mental retardation understand death, dying, and loss. It covers the concept of death; experiencing and coping with grief, mourning, comfort, and support; and death-related rituals (visitations and funerals). The curriculum consists of five in-class lessons and one field trip, emphasizing active participation through both verbal and visual presentation of materials. The instructor's guide provides a script for each lesson and includes guidelines for planning and administering each lesson. Each participant has a student notebook that accompanies the instructor's training curriculum. Each participant chooses a support person to help him/her review the lessons and complete assignments. Item No. 100.014—<http://www.uic.edu/orgs/rrtcamr/>.

Planning for the Future: A Guide for Families and Friends of People with Developmental Disabilities (1997). New York State Developmental Disabilities Planning Council.

Pooled Trust Programs for People with Disabilities: A Guide for Families. The Arc of the United States (2001). Pooled trusts enable families

to pool their resources into a “master” special needs trust to protect their relatives’ government benefits while increasing the total funds available for investment and reducing families’ share of administrative costs. This publication has a question-and-answer format that provides a clear understanding of pooled trust programs and serves as a guide to help families and professionals evaluate this future planning option. It also contains a directory of known pooled-trust programs in the United States for people with disabilities and provides an overview of using various trusts as a financial planning tool. www.TheArc.org.

Health promotion

Communication and sensory issues

The American Foundation for the Blind (AFB). AFB is dedicated to addressing the critical issues of literacy, independent living, employment, and access through technology for the 10 million Americans who are blind or visually impaired. AFB has several fact sheets related to low vision and vision disabilities.

- Normal Changes in the Aging Eye 08/19/1999
- Creating a Comfortable Environment for Older Individuals Who are Visually Impaired 09/09/2000
- Low Vision and Older Persons 09/01/2000
- How to Recognize Vision Loss in Older People 11/04/1999
- Visual Impairment and Age-related Macular Degeneration 06/04/1999
- Special Services to Help Older Persons Experiencing Vision Loss 01/19/1999
- Visual Impairment and Glaucoma 04/11/1999
- Cataracts 02/07/1999
- The Human Eye, Its Functions, and Visual Impairment 10/22/1999
- Visual Impairment and Diabetic Retinopathy 03/02/1999
- Tips for Making Print More Readable 08/15/1998

<http://www.afb.org/>. Tel: (800) AFB-LINE (800-232-5463), E-mail: afbinfo@afb.net, Tel: (212) 502-7600, Fax: (212) 502-7777, 11 Penn Plaza/Suite 300, New York, NY 10001.

American Speech-Language-Hearing-Association (ASHA). The web site has information and brochures on a variety of topics related to speech, language, and hearing. <http://www.asha.org/consumers/brochures/brochures.htm>.

IASSID International Consensus Statement: Early Identification of Hearing and Visual Impairment in Children and Adults with an Intellectual Disability. H.M. Evenhuis and L.M.D. Nagtzaam, editors (1997/98). Leiden, the Netherlands and Manchester, United Kingdom: IASSID Special Interest Research Group on Health Issues. <http://www.iassid.org/pdf/sensory-imp-consensus.pdf>.

National Institute on Deafness and Other Communication Disorders (NIDCD)—Health Information Directory of Organizations. The NIDCD Directory lists organizations that are national in scope and that focus on health issues relating to hearing, balance, smell, taste, voice, speech, and language. <http://webdb.nidcd.nih.gov/resdir/resourc.html>.

Exercise and nutrition

Achieving a Beneficial Fitness: A Program and a Philosophy in Mental Retardation: Contemporary Issues in Health, Vol. 1, No. 1. J. Rimmer (2000). American Association on Mental Retardation (AAMR). This book discusses the benefits of health promotion activities for individuals with mental retardation. It includes guidelines on developing innovative health and fitness programs. *RRTC on Aging with Developmental Disabilities*, The University of Illinois at Chicago. <http://www.uic.edu/orgs/rrtcaml/> or <http://www.AAMR.org>.

Aging, Mental Retardation and Physical Fitness. J. Rimmer. (1997). This fact sheet provides an overview of what physical fitness is and how it relates to older people with mental retardation. It includes helpful guidelines for family members, support people, service providers, and others interested in starting a program for older individuals with mental retardation. *RRTC on Aging with Developmental Disabilities*, The University of Illinois at Chicago. Item No. 500.011—<http://www.uic.edu/orgs/rrtcaml/>.

Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities. T. Heller, B.A. Marks, and S.H. Ailey (2001). This innovative curriculum is a 12-week interactive program specifically designed for individuals with developmental disabilities (DD). Each week, participants enjoy three 1-hour sessions, where they are encouraged to understand their attitudes toward health, food and exercise; to gain skills and knowledge about healthy eating and exercising; to identify food, and exercise preferences; to participate in food preparation and exercise activities; and to locate places in their community where they can exercise regularly. Strategies woven throughout this curriculum include making choices, self-determination, self-efficacy, self-advocacy, and rights and responsibility, along with problem-solving techniques and conflict resolution. Direct staff or health professionals can easily adapt the curriculum to meet the unique needs and capacities of individuals with DD and their agencies.

The National Center on Physical Activity and Disability (NCPAD). This is a national resource for information on physical activity and disability. NCPAD gathers information on current research, local programs, adapted equipment, recreation and leisure facilities, and many other aspects of physical activity for persons with disabilities. <http://www.ncpad.org>.

Removing Barriers to Health Clubs and Fitness Facilities: A Guide for Accommodating All Members, Including People with Disabilities and Older

Adults. The North Carolina Office on Disability and Health. This guide provides ways to make a health club's facility and services more accessible to all people, including people with disabilities and older adults. <http://www.fpg.unc.edu/~ncodh/FitnessGuide.pdf>.

Special Olympics. As an international organization, Special Olympics provides opportunities for individuals with intellectual disabilities to participate in sports training and competition. <http://www.SpecialOlympics.org>.

Mental health issues

Assessing Psychopathology and Behavior Problems in Persons with Mental Retardation: A Review of Available Instruments. M. Aman (1991). Washington, D.C: U.S. Department of Health and Human Services.

Behavioral Phenotypes of Genetic Syndromes: A Reference Guide for Psychiatrists. M. Moldavsky, D. Lev, and T. Lerman-Sagie. *Journal of American Academy of Child and Adolescent Psychiatry* 2001;40: 749–61.

Handbook of Mental Health Care for Persons with Developmental Disabilities. R. Ryan. Persons with developmental disabilities are vulnerable to the same mental health conditions as other people, and all forms of treatment, including psychotherapy, can be effective. Dr. Ryan's book provides practical approaches for individuals who have a strong need for extraordinary care. <http://www.diverse-city.com/display.htm>.

Personality Development in Individuals with Mental Retardation. E. Zigler and D. Bennett-Gates, editors. New York: Cambridge University Press; 1999. p. 206–25.

Pharmacologic Management of Psychiatric and Behavioral Symptoms in Mental Retardation. A. Madrid, M. State, B. King. *Child Adolescent Psychiatric Clinics of North America*. 2000;9:225–43.

Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation. N. Bouras, editor. New York: Cambridge University Press; 1999. p. 464.

Treating Mental Illness and Behavior Disorders in Children and Adults with Mental Retardation. A. Dosen and K. Day, editors. Washington, D.C.: American Psychiatric Press, Inc.; 2001.

What Psychotherapists Should Know About Disability. R. Olkin. Berkeley, CA: Guilford Press; 1999. This book, based on the social model of disability, provides the information and skills mental health professionals need for effective, informed work with clients with disabilities.

Sexuality

The Ethics of Touch: Establishing and Maintaining Appropriate Boundaries in Service to People with Developmental Disabilities.

D. Hingsburger and M. Harber (1997). All human beings need to touch, to be held, and to hold. “This training package looks at the delicate issue of touch. Those who provide direct care to people with developmental disabilities are often asked to be in private places performing intimate services. From bathing to toileting to dressing, we are necessarily in close proximity to those we serve. Given this situation, it is imperative that staff be aware of how to provide these services while maintaining appropriate professional boundaries. How do we appropriately express affection toward those we serve? This video suggests new and healthy ways of helping people with disabilities fulfill their deepest needs.” <http://www.diverse-city.com/display.htm>.

Finger Tips: A Guide for Teaching about Female Masturbation. D. Hingsburger and S. Haar (2000). This book and video set teaches women with developmental disabilities about masturbation. Finger Tips also confronts typical myths about female sexuality. A gentle, positive film that is clear, graphic, and dignified. The book includes a step-by-step photographic essay about masturbation, and the joy of private time for women with developmental disabilities. <http://www.diverse-city.com/display.htm>.

Hand Made Love: A Guide for Teaching About Male Masturbation. This book and video set by D. Hingsburger (1995) discusses privacy, pleasure, and the realities of sharing living spaces with others. The narrator of the video talks about myths and suggests that masturbation can be a way of learning about sex, while the book discusses masturbation from the point of view of both health and pleasure. <http://www.diverse-city.com/display.htm>.

Sexuality Series: STARS 1: Skills Training for Assertiveness Relationship-Building and Sexual Awareness; At Greater Risk: Legal Issues in Sexual Abuse of Adults with Developmental Disabilities—A Training Guide for Care Givers; STARS 2: Beginnings, and Doubly Silenced. S. Heighway and S. Webster. Wisconsin Council on Developmental Disabilities (1990). This five-part curriculum may be used by faculty, supervisors, caregivers, or consumers to promote understanding about sexuality and relationships, social interaction; sexual awareness; assertiveness, and prevention of sexual abuse. <http://ici2.coled.umn.edu/rte/dspttr/resources/rsrc257.html>.

The Sexuality Information and Education Council of the United States (SIECUS). SIECUS is a national, nonprofit organization affirming that sexuality is a natural and healthy part of living. Incorporated in 1964, SIECUS develops, collects, and disseminates information; promotes comprehensive education about sexuality; and advocates the right of individuals to make responsible sexual choices. <http://www.siecus.org/>.

Under Cover Dick: A Guide for Teaching about Condom Use Through Video and Understanding. D. Hingsburger (1996). This book and video set provides information about teaching condom use. The video presents the topic of disease transmission as well as demonstrates how to wear a condom.

The book includes photographs of each step involved. <http://www.diverse-city.com/display.htm>.

Self-esteem

Shaking off Stereotypes (1996). A film addressing issues of self-esteem and personal pride. Actress and disability rights activist, Joy Mincey Powell, plays Samantha, a young woman with low self-confidence. Everyone Sam meets tells her she's not qualified, she can't do the job, and her disability is too great an obstacle. Advocating Change Together (ACT), 1821 University Avenue/Suite 306-S, St. Paul, MN 55104, 800 641-0059, <http://www.selfadvocacy.com>.

Violence, abuse, and disability

A Thousand Words. C. Caprio-Orsini (1996). Study after study documents that people with disabilities are the most victimized in our society is a statistical fact. Caprio-Orsini shares her approach to therapy and healing. This is a book about hope rising out of the ashes of violence. <http://www.diverse-city.com/display.htm>.

Developmental Disabilities Center. The J.P. Das Developmental Disabilities Center web site from the University of Alberta in Edmonton, Canada, hosts the International Coalition on Abuse and Disability Listserv (ICAD-L). ICAD-L is an electronic mail network on the topic of abuse and disability. List members include researchers, clinicians, people with disabilities, parents, and others interested in this topic. <http://www.quasar.ualberta.ca/ddc/development/index.html>.

Issues on Violence and Women with Developmental or Other Disabilities. Impact 2000;13(3). An excellent issue presenting several articles and resources regarding violence against women with developmental disabilities. Research and Training Center on Community Living, The Institute on Community Integration (UAP), The College of Education and Human Development. <http://ici.umn.edu/products/impact/133/default.html>.

Just Say Know! D. Hingsburger. The book explores the victimization of people with disabilities and helps reduce the risk of sexual assault. It presents the skills to teach people with disabilities, enabling them to protect themselves, as well as new ways of looking at the indicators of sexual abuse in the population of people who have developmental disabilities. <http://www.diverse-city.com/display.htm>.

Women's health issues

Aging with Developmental Disabilities: Women's Health Issues. A. Brown and L. Murphy (1999). This fact sheet provides information on age-related health issues for women with developmental disabilities based on

the research to date. The fact sheet addresses the most commonly asked questions by women who are aging (eg, menopause, osteoporosis, and heart disease) and how to stay healthy. It includes a list of related resources for women who want more information. RRTC on Aging with Developmental Disabilities, The University of Illinois at Chicago. Item No. 500.015—<http://www.uic.edu/orgs/rrtcamr/>.

Breast Health Access for Women with Disabilities (BHAWD). BHAWD is a model of comprehensive breast health services tailored to the functional abilities and special needs of women with physical and vision impairments. <http://www.bhawd.org>.

Center for Research on Women with Disabilities (CROWD). A research center focusing on issues related to health, aging, civil rights, abuse, and independent living for women with disabilities to promote, develop, and disseminate information for expanding the life choices of women with disabilities so they may participate fully in community life. <http://www.bcm.tmc.edu/crowd/>.

The National Women's Health Information Center. The Office on Women's Health, U.S. Department of Health and Human Services. This web site provides information for women with disabilities, and for caretakers, health professionals, and researchers to address the challenges involved. <http://www.4women.org/wwd/index.htm>.

Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being. D.M. Krotoski, M.A. Turk, and M.A. Nosek, editors. Baltimore: Paul H. Brookes. The book addresses a broad range of issues, including sexuality and reproduction; love, marriage, and relationships; bowel and bladder management; stress; and physical fitness. It was written by researchers and women with disabilities.

Women with Developmental Disabilities: Health & Aging Electronic Mailing List. Women's health forum for aging and developmental disabilities/mental retardation. <http://listserv.uic.edu/archives/womhlthaging-dd.html>, or e-mail list owner lisab@uic.edu.

Legislation

The Education for All Handicapped Children Act of 1975 (P.L. 94-142) guaranteed children with disabilities the right to a “free, appropriate public education” in the “least restrictive environment.” On June 2, 1997, President Bill Clinton reauthorized this law, which was renamed the Individuals with Disabilities Education Act subsequent to its original enactment. The Education For All Handicapped Children Act began the process of ending segregated schools for disabled children. It guaranteed disabled children throughout the nation—for the first time in our history and in any country in the world—a right to a public education.

Fair Housing Act of 1968. (October 1, 1996). A guide to disability rights laws. U.S. Department of Justice, Civil Rights Division, Disability Rights

Section. “The Fair Housing Act, as amended in 1988, prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and national origin. Its coverage includes private housing, housing that receives Federal financial assistance, and State and local government housing. It is unlawful to discriminate in any aspect of selling or renting housing or to deny a dwelling to a buyer or renter because of the disability of that individual, an individual associated with the buyer or renter, or an individual who intends to live in the residence. Other covered activities include, for example, financing, zoning practices, new construction design, and advertising.” <http://www.usdoj.gov/crt/ada/cguide.htm>.

Individuals with Disabilities Education Act (October 1, 1996). A guide to disability rights laws. U.S. Department of Justice, Civil Rights Division, Disability Rights Section. Retrieved June 1, 1998 from the World Wide Web: <http://www.usdoj.gov/crt/ada/cguide.htm>. “The Individuals with Disabilities Education Act (IDEA) (formerly called P.L. 94-142 or the Education for all Handicapped Children Act of 1975) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs.” “IDEA requires public school systems to develop appropriate Individualized Education Programs (IEPs) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student.” “IDEA also mandates that particular procedures be followed in the development of the IEP. Each student’s IEP must be developed by a team of knowledgeable persons and must be at least reviewed annually. The team includes the child’s teacher; the parents, subject to certain limited exceptions; the child, if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents’ or agency’s discretion. If parents disagree with the proposed IEP, they can request a due process hearing and a review from the State educational agency if applicable in that state.”

Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112) states that “No otherwise qualified individuals with disabilities in the United States shall solely by reason of his disability be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” Section 504 prohibits all recipients of federal financial assistance from discriminating on the basis of disability in their programs and activities, including their employment practices. Though many Americans might overlook its significance, the effects of Section 504 are, today, visible everywhere—not only in the ramps and curb cutouts that make our environment accessible to all, but in the greatly increased presence of people with disabilities at every level of our common life. This legislation set the stage for the ADA (Americans with Disabilities Act) in 1990. Moreover, 504 obligates entities receiving federal funding to include universal design features in newly constructed and

altered buildings (including accessible bathrooms, ramps, curb cuts, etc.), and to ensure that people with disabilities are not excluded from programs and activities on the basis of disability. Section 504 also provided funding for the development of Centers for Independent Living (CIL); only a few existed prior to 1977, whereas today hundreds of them exist in rural and urban communities across the country.

The Americans with Disabilities Act (ADA) (P.L. 101-336) (October 1, 1996). A guide to disability rights laws. U.S. Department of Justice, Civil Rights Division, Disability Rights Section. The ADA is a sweeping mandate to end discrimination on the basis of disability in employment, transportation, public accommodations, telecommunications, and state and local governments. The ADA was signed into law by President George Bush on July 26, 1990. It stands with women's suffrage and the Civil Rights Act in the effort to bring fundamental rights and equality to all Americans. For the disability community and parents of children with disabilities, these events are the equivalent of *Brown versus Board of Education*, and the repeal of Jim Crow laws. And although not all Americans with disabilities know about these events, they deeply feel the consequences of the revolution: they, and their families, recognize that some profound change in the early 1980s allowed them to have access to the world, far more easily than previously. Curb cuts, handicap parking places, specially equipped bathrooms, and other improvements made their expectations and sense of possibility grow. <http://www.usdoj.gov/crt/ada/cguide.htm>.

Professional associations advocating/researching issues in persons with I/DD

The Administration on Developmental Disabilities (ADD). Seeks to ensure that individuals with developmental disabilities and their families have access to culturally competent services and supports that promote independence, productivity, integration, and inclusion into the community. ADD oversees the State Councils on Developmental Disabilities, State Protection and Advocacy Program for People with Developmental Disabilities (PADD), National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Services (UCEDD), and Projects of National Significance (PNS). <http://www.acf.dhhs.gov/programs/add/index.htm>.

American Association on Mental Retardation (AAMR). AAMR promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual disabilities. AAMR, along with The Arc, is a founding member of the U.S. International Council on Developmental Disabilities. <http://www.aamr.org>.

American Society on Aging—Network on Environments, Services and Technologies to Maximize Independence (NEST). NEST brings together

professionals working with older adults who have life-long and late-life physical, sensory, and/or cognitive disabilities. Maximizing Human Potential is the quarterly newsletter designed to share information across aging, rehabilitation, and disability systems about best practices and innovative programs; research that describes the need for assistive environments, services, and technologies; and evaluates their impact on function, behavior, quality of life, and quality of care; trends in policy and funding; and strategies for advocacy and systems change. <http://www.asaging.org/>.

The Arc of the United States. It works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community. Various publications are available on issues relating to intellectual and developmental disabilities. <http://www.thearc.org/>.

The Developmental Disabilities Nurses Association. A professional organization for nurses serving individuals with developmental disabilities. <http://www.ddna.org/>.

The International Association for the Scientific Study of Intellectual Disabilities. IASSID is an international and interdisciplinary scientific organization that promotes worldwide research and exchange of information on intellectual disabilities. www.iassid.org.

International Association for the Scientific Study of Intellectual Disabilities. Special Interest Group on Aging and Intellectual Disability (SIRGAID). SIRGAID is an international network of researchers, clinicians, providers, administrators, and others who are interested in furthering the study of aging in people with intellectual disabilities. www.iassid.org.

National Association of Developmental Disabilities Councils. NADDC provides support and assistance to member Councils in order to promote a consumer- and family-centered system of services and supports for those with developmental disabilities. It is a national organization for Developmental Disabilities Councils that advocates and works for change on behalf of people with developmental, as well as other, disabilities, and their families. <http://www.naddc.org/>.

University Centers for Excellence (UCEDDs) (formerly called UAPs). “Currently Association of University Centers on Disabilities (AUCD) has 61 UCEDDs with at least one found in every state and territory in the U.S. Each is affiliated with a major research university. AUCD has also established Developmental Disabilities Research Centers (DDRC) and Maternal and Child Health Leadership Education in Neurodevelopmental and Related Disabilities (LEND) which serve to meet the needs established in the Presidents Panel on Mental Retardation. Leadership Education in Neurodevelopmental and Related Disabilities programs provide long-term, graduate level interdisciplinary training to health professionals.” http://www.aucd.org/aucd_lend.htm

World Health Organization – Aging and Health Programme. www.who.org.

Rehabilitation research training centers and disability

Funded by the U.S. Department of Education

Disability Statistics Center. A rehabilitation research and training center that produces and disseminates statistical information on disability and the status of people with disabilities in the United States. <http://dsc.ucsf.edu/UCSF/>.

Center on Self-Determination, Oregon Health & Science University. The Center's mission is to identify, develop, validate, and communicate policies and practices that promote the self-determination of people with and without disabilities. <http://cdrc.ohsu.edu/selfdetermination/selfdet.html>.

National Resource Center on Community Integration. The Center distributes bulletins, research reports, articles, information packages, and other materials on a broad range of topics related to integration or inclusion for people with disabilities, and, specifically, those who have been labeled mentally retarded and developmentally disabled. Topics include agency change/positive practices, community supports/integration, family supports, friendships/relationships, gender and disability, housing, inclusion, multiculturalism and disability, recreation and leisure, self-advocacy, supported employment, and supported living. <http://web.syr.edu/~thechp/nrc.htm>.

Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC-ADD), The Department of Disability and Human Development, College of Applied Health Sciences, University of Illinois at Chicago. The RRTC-ADD's mission is to promote the independence, productivity, community inclusion, full citizenship, and self-determination of older adults with mental retardation through a coordinated program of research, training, technical assistance, and dissemination activities. Various publications are available on issues relating to aging and intellectual/developmental disabilities: <http://www.uic.edu/orgs/rrtcamlr>.

The Rehabilitation Research and Training Center on Health and Wellness, Oregon Health and Science University. The RRTC on Health and Wellness conducts research and training to support health and wellness of persons with long-term disabilities, including conditions of cerebral palsy, multiple sclerosis, postpolio syndrome, amputation, and spinal cord injury. <http://www.healthwellness.org/index.htm>.

Research and Training Center on Rural Rehabilitation Services, The University of Montana Rural Institute, Missoula, Montana. A center of excellence for disabilities education, research, and services. Scientific methods are used to develop solutions to these wide-ranging problems including access to transportation and housing, employment and self-employment, independent living services, health and wellness facilities, and inclusion in community planning and activities. <http://ruralinstitute.umt.edu/rtrcrural/>.