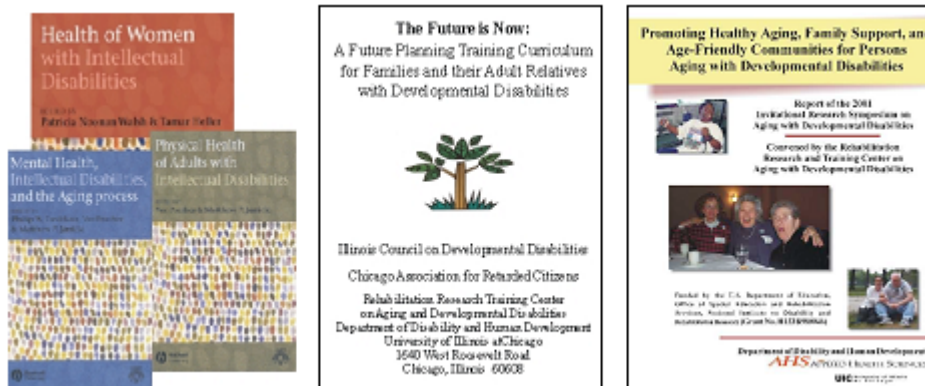


Resources on Aging with Intellectual/ Developmental Disabilities

Selected Products and Publications January 2010

The Rehabilitation Research and Training Center on
Aging with Developmental Disabilities
Department of Disability and Human Development
University of Illinois at Chicago



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Funded by the United States Department of Education, Office of Special Education, and Rehabilitative Services,
National Institute on Disability and Rehabilitation Research, Cooperative Agreement #H133B080009

HEALTH PROMOTION

NEW! Haveman, M.J., Heller, T., Lee, L.A, Maaskant, M.A, Shooshtari, S., Strydom, A. (2009). Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities. IASSID Special Interest Research Group on Ageing and Intellectual Disabilities/Faculty Rehabilitation Sciences, University of Dortmund.

This paper summarizes a review of the scientific literature over the past fifteen years on the topic of health risks associated with ageing in people with an Intellectual Disability. It is a review of descriptive observational research ranging from discussion at the social 'wellness' end of the spectrum through to analysis of the impact of ageing on the incidence of chronic physical illness.

ITEM NO: 520.110

It can be downloaded at no charge from the RRTCADD website www.rrtcadd.org

Dementia and People with Intellectual Disabilities: What Can We Do? Dalton, A., Janicki, M., & McCallion, P. (Executive Producers), Albany, NY: The New York State Developmental Disabilities Planning Council

This CD-ROM video explains how adults with I/DD are affected by dementia and depicts their functional changes over time. It presents guidelines for early screenings and diagnostic assessments; explains how clinical supports can support persons with dementia and their carers; and recommends program adaptations, environmental modifications, and specialized care that enable individuals to remain in their home for longer periods of time. This 23-minute video was filmed in 2001.

ITEM NO. 510.013

COST PER UNIT: \$15.00

Health promotion pilot programs evaluation: Improving Athletes' health (2005). Prepared by the RRTC on Aging with Developmental Disabilities & Special Olympics.

This report describes the outcomes of a health promotion program for Special Olympics (SO) athletes at 6 sites. The evaluation focused on health status and health behaviors among SO athletes, program satisfaction among coaches and SO athletes, and process and structural variables associated with implementation of health promotions within the SO organization. **For more information, contact Special Olympics at 202-824-0269 or <http://www.specialolympics.org>.**

RRTCADD Disability Research Brief: Body weight status of adults with intellectual disabilities (2006). Yamaki, Kiyoshi

This brief compares the rates of obesity between adults with and without I/DD from 1985 to 2000. It is based on an analysis of the National Health Interview Surveys.

ITEM NO: 510.008

COST PER UNIT: \$3.00. It can be downloaded at no charge from the RRTCADD website www.rrtcadd.org

Geriatrics (2006). Pekala Service, K., Tyler, Jr., C.V., & Janicki, M.P. , pp. 575-589.

This chapter is in the book *Medical Care for Children and Adults with Developmental Disabilities* (2nd Ed.) edited by I. Leslie Rubin, M.D. and Allen Crocker, M.D. It describes the age-related health and psychosocial issues of older adults with I/DD. Topics include chronic disease, preventive health care, geriatric assessment, medication issues, dementia, end of life care, and the difficulties of medical diagnosis and treatment.

ISBN: 978-1-55766-766-3

COST PER UNIT: \$125.00

Order directly from Brookes Publishing Co. at www.brookespublishing.com or by calling 1-800-638-3775

HEALTH PROMOTION

Physical Activity and Fitness. (2005). Rimmer, James H. & Hiss, S. Blythe. 87-128.

This chapter is part of a larger collection entitled Health Promotion for Persons with Intellectual and Developmental Disabilities. It is published by the American Association on Mental Retardation (AAMR) in Washington DC. It can be ordered online at the website or by phone.

ISBN: 0-940898-91-8

COST PER UNIT: \$39.95

Order directly from AAMR publishing at <https://bookstore.aaid.org/> or by calling 301-604-1340

Fact sheets for healthy aging (2005). Pederson, E. & Nelis, T.

The RRTCADD's Facts for Healthy Aging educates adults with disabilities about health conditions and impairments that typically occur in later life. Each fact sheet provides a concise and understandable explanation of the cause, symptoms and treatments of a specific health condition. These fact sheets were adapted from the "Age Pages" series for the general population developed by the National Institute on Aging. Currently available fact sheets are:

ITEM NO. 510.023	Foot Care
ITEM NO. 510.024	High Blood Pressure
ITEM NO. 510.025	Exercise
ITEM NO. 510.026	Arthritis

COST PER UNIT: \$5.00 for a set of four fact sheets. Can download at no charge from: www.rrtcadd.org

Revised 3rd Edition **Exercise and nutrition health education curriculum for adults with developmental disabilities,** (2006, 3rd Ed.). Heller, T., Marks, B.A., & Sisirak, J.

In the 3rd edition of this innovative curriculum, we added twenty-four new modules based on our teaching experiences with participants of the University of Illinois at Chicago (UIC) Community-Based Train-the-Trainer Health Promotion Program. The new modules were developed for agency staff to introduce core concepts related to physical activity, exercise, and nutrition to persons with intellectual and developmental disabilities (I/DD).

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 that are 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 RRTCADD can provide regional train-the-trainer sessions for agencies or groups to familiarize facilitators with the curriculum philosophy, goals and training materials. Training session(s) simulate experiences similar to the actual health education program. Trainers-in-training are encouraged to complete exercises that they will ask future participants to do.

Table of Contents and Sample Files from the Curriculum:

http://www.rrtcadd.org/Research/HP/Related_Project/Staff_Education/Curriculum/content.html

ITEM NO: 520.011	COST PER UNIT: \$75.00 (Soft cover)
ITEM NO: 520.010	COST PER UNIT: \$25.00 (CD-ROM)

HEALTH PROMOTION

Mental health, intellectual disabilities and the aging process, (2003). Davidson, P.W., Prasher, V.P., & Janicki, M, P.

Evidence suggests that mental health disorders may occur in up to half of all people with intellectual disability and that these disorders accelerate significantly with age. This book discusses the mental health and behavior needs of adults with intellectual disabilities. It is a major sourcebook on mental health conditions and treatment choices for this population.

ISBN: 1-405-101644 COST PER UNIT: \$44.95

Order directly from Wiley at <http://www.wiley.com/WileyCDA/>

Aging, mental retardation and physical fitness, (1997). Rimmer, J.

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.

ITEM NO.: 500.011 COST PER UNIT: \$3.00 for a bound copy
Can be downloaded at no charge from: www.rrtcadd.org.

The nursing clinics of North America: Intellectual and developmental disabilities, (2003).
Volume 38, No. 2. Hahn, Joan Earle & Marks, Beth A.

This quarterly journal issue reviews new diagnostic and nursing management techniques for individuals with intellectual and related developmental disabilities. Articles address a variety of adult/late life concerns including health promotion, sexuality, the nurse's role in caring for older people, nursing care resources, and support through assistive technologies.

ISSN: 0029-6465 COST PER UNIT: \$51.00
Order directly from W.B. Saunders Company at www.wbsaunders.com or 1-800-654-2452

The Tampa Scientific Conference on Intellectual Disability, Aging, and Health: Final report, (2003). Davidson, P.W., Heller, T., Janicki, M, P., & Hyer, K.

This report identifies the gaps in knowledge about the health of older persons with intellectual and related developmental disabilities. It contains a research agenda for health and mental health outcomes based on the recommendations of the 75 researchers, health professionals, older adults with disabilities, and families who participated in this international conference.

ITEM NO.: 520.028 COST PER UNIT: \$10.00 per bound copy.
Can be downloaded at no charge from: www.rrtcadd.org

Physical health of adults with intellectual disabilities, (2002). Prasher, V.P. & Janicki, M.P.

This book presents the latest research on health issues and health promotion and their implications for adults with intellectual disabilities who are aging. It is an excellent primer on health issues and treatment considerations for practice, research and teaching.

ISBN: 1-405-10219-5 COST PER UNIT: \$47.95 **Order directly from Wiley** at
<http://www.wiley.com/WileyCDA/>

HEALTH PROMOTION

Health of women with intellectual disabilities, (2002). Walsh, P.N. & Heller, T.

This book presents the latest research on age-related health issues for women with intellectual disabilities. Chapters written by leading international researchers and practitioners address a variety of concerns including later life health risks, reproduction and sexuality, mental health, and health promotion. Complementary chapters discuss innovative health education and health support interventions and recommend progressive policies to improve health care for women with intellectual disabilities.

ISBN: 1-405-10103-2 COST PER UNIT: \$50.95 Order directly from Wiley at
<http://www.wiley.com/WileyCDA/>

Aging with mental retardation: Oral health for older individuals with disabilities, (2001). Farsai, P., & Calabrese, J.

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.

ITEM NO: 500.023 COST PER UNIT: \$3.00 per bound copy.
Can be downloaded at no charge from: www.rrtcadd.org.

Achieving a beneficial fitness: A program and a philosophy in mental retardation: Contemporary issues in health, Vol.1, No. 1, (2000). Rimmer, J. 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.

ISBN 0-940898-71-3 COST PER UNIT: \$11.95 (\$8.95 AAMR members)
Order directly from the publisher by calling the AAMR at (301) 604-1340, or by accessing their web site at: www.aamr.org.

Ageing and intellectual disabilities: Improving longevity and promoting healthy aging, (2000). Ageing and Intellectual Disabilities Special Interest Research Group (SIRG) of The International Association for the Scientific Study of Intellectual Disability (IASSID).

This series of reports is the outcome of an international initiative to promote the longevity and healthy aging of adults with intellectual disabilities that was jointly organized by the IASSID and the World Health Organization. Work groups of international researchers in aging and intellectual disabilities synthesized the latest research and developed recommendations that produced five reports: [Physical Health issues](#), [Biobehavioral issues](#), [Women's Health](#), [Ageing and Social Policy](#), and a [Summative Report](#).

ITEM NO.: 610.008 COST PER UNIT: \$25.00 (set of 5 bound reports)
Can be downloaded at no charge from the report links above

McCracken Intervention Matrix: Guidelines for carers to help older adults with mental retardation maintain optimal functioning, (1997). McCracken, A., & Lottman, T.

This guidebook assists carers to help older people with mental retardation maintain optimum functioning in nine areas: eating and nutrition; elimination; motor skills; awareness and thinking; communication; relationships; protection and assertiveness; sexual awareness and behavior; and assistance and acceptance. Each of the nine modules includes an overview of age-related changes, guidelines for detecting changes in function, and easy-to-implement activities to help individuals maintain optimum functioning. The guidebook also contains an overview of the aging process and a resource directory for additional information on aging with mental retardation.

ITEM NO.: 500.009 COST PER UNIT: \$30.00

HEALTH PROMOTION

Aging with developmental disabilities: Changes in vision, (1996). Flax, M.E., & Luchterhand, C.

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?

ITEM NO.: 500.003 **COST PER UNIT: \$3.00 for a bound copy; Can be downloaded at no charge from:**
www.rrtcadd.org.

JOURNAL ARTICLES: (\$3.25 EACH)...

New! **Health Status and Activities of Daily Living and Walking in Older People with Intellectual Disabilities, 510.011** (2009). Henderson, M.C., Acquilano, J.P., Meccarello, J.C., Davidson, P.W., & Janicki, J. Journal of Policy and Practice in Intellectual Disabilities, 6 (4), 282-286.

New! **New Voices in Women's Health: Perceptions of Women with Intellectual and Developmental Disabilities, 520.111** (2009). Brown, A.a. & Gill, C.J. Intellectual and Developmental Disabilities, 47 (5), 337-347.

New! **Neurodevelopmental conditions and aging: Report on the Atlanta Study Group Charrette on 500.027 Neurodevelopmental Conditions and Aging, (June 2008). Janicki, M., Henderson, M.C., Rubin, L.I., Disability and Health Journal. 1, 116-124**

New! **Report of the State of the Science in Aging with Developmental Disabilities: Charting Lifespan 500.028 Trajectories and Supportive Environments for Healthy Community Living Symposium. (June 2008). Heller, T. Disability and Health Journal. 1, 127-130**

New! **Health services, health promotion, and health literacy: Report of the State of the Science in Aging with 500.030 Developmental Disabilities Conference (June 2008). Marks, B., Sisirak, J., Hsieh, K. Disability and Health Journal. 1, 136-142.**

New! **Environmental barriers and supports to the health, function, and participation of people with 500.031 developmental and intellectual disabilities: Report of the State of the Science in Aging with Developmental Disabilities Conference (June 2008). Hammel, J., Jones, R., Smith, J., Sanford, J., Bodine, C., Johnson, M. Disability and Health Journal. 1, 143-149.**

New! **Ascertaining Health-Related Information on Adults With Intellectual Disabilities Development and Field 520.107 Testing of the Rochester Health Status Survey, (March 2008) Davidson, P., Henderson, M.C., Janicki, M., Robinson, L.M., Bishop, K. M., Wells, A., Garroway, J., Wexler, O. Journal of Policy and Practice in Intellectual Disabilities. 5 (1), 12-23.**

New! **Carer reports of health status among adults with intellectual/developmental disabilities in Taiwan living 500.026 at home and institutions. (2007). Wang, K.-Y., Hsieh, K, Heller, T., Davidson, P.W., & Janicki, M.P. Journal of Intellectual Disability Research 51(3), 173-183.**

New! **Health Perceptions of Latinos with Intellectual Disabilities: The Results of a Pilot Study. (2008). 520.109 Jurkowski, J., Rivera, Y., Hammel, J. Health Promotion Practice. Early view available 10/1/08.**

500.024 Psychometric Evaluation of a Self-Reported Measure of Depression for Individuals with Mental Retardation, (2005). Esbensen, A. J., Seltzer, M. M., Greenberg, J. S., & Benson, B. A. American Journal of Mental Retardation, 110, 469-481

520.103 Promoting Physical Activity Among Older People, (2005). Hughes, S. L., Prohaska, T. R., Rimmer, J. H., Heller, T. Generations, 29(2), 54-59.

510.005 Group home care for adults with intellectual disabilities and Alzheimer's disease, (2005). Janicki, M. P., Dalton, A. J., McCallion, P., Baxley, D. D., Zendell, A. Dementia, 4(3), 361-385.

530.006 Body weight status among adults with intellectual disability in the community, (2005) Yamaki, K. Mental Retardation, 43(1), 1-10.

HEALTH PROMOTION

- 520.105** **Examining Barriers and Supports to Community Living and Participation After a Stroke from a Participatory Action Research Approach** (2006) Hammel, J., Jones, R., Gossett, A & Morgan, E. Topics in Stroke Rehabilitation, 13(3), 43-58.
- 520.106** **Evaluating an Interpersonal Model of Depression Among Adults with Down Syndrome**, (2006) Ailey, S.H., A.M., Heller, T., & Smith, E.V. Research and Theory for Nursing Practice, 20, 229-246.
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- American Journal on Mental Retardation** Special Issue on Aging, Volume 109, No.2 March 2004.
Guest Editor: Marsha M. Seltzer, Ph.D.
- 520.100** **Improvements in Physical Fitness in Adults With Down Syndrome**. (2004). Rimmer, J.H., Heller, T., Wang, E., Valerio, I. Pp. 165-174.
- 520.101** **Attitudinal and Psychosocial Outcomes of a Fitness and Health Education Program on Adults With Down Syndrome**. (2004). Heller, T., Hsieh, K., Rimmer, J.H. pp. 175-185.
- 520.102** **Nutritional Status and Risk Factors for Chronic Disease in Urban-Dwelling Adults With Down Syndrome**. (2004). Braunschweig, C.L., Gomez, S., Sheean, P., Tomey, K.M., Rimmer, J.H., Heller, T. pp.186-193.
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- Journal of Policy and Practice in Intellectual Disabilities**, March 2004, Volume 1, Issue 1 Editor-in-chief: Matthew Janicki, Ph.D., RRTCADD Associate Director
- 510.100** **Genetically Linked Syndromes in Intellectual Disabilities**. (2004). Henderson, C.M., pp.31-41
To subscribe contact Wiley at <http://www.wiley.com/WileyCDA/> or 1-800-216-2522.
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- 530.005** **Beyond the disability: Recognizing mental health issues among persons with intellectual and developmental disabilities**, (2003). Ailey, S.H. The Nursing Clinics of North America: Intellectual and Developmental Disabilities, 38(2), 313-329.
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- 520.027** **Bridging the equity gap: Health promotion for adults with intellectual and developmental disabilities**, (2003). Marks, B.A., & Heller, T. The Nursing Clinics of North America: Intellectual and Developmental Disabilities, 38(2), 205-228.
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- 520.023** **Adaptive behavior and cognitive function of adults with Down syndrome: Modeling change with age**, (2003). Hawkins, B.A., Eklund, S.J., James, D.R., & Foose, A.K. Mental Retardation, 41(1), 7-28.
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- 520.026** **The Edinburgh principles with accompanying guidelines and recommendations**, (2002). Wilkinson, H., & Janicki, M.P. Journal of Intellectual Disability Research, 46(3), 279-284.
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- 520.021** **Barriers and supports for exercise participation among adults with down syndrome**, (2002). Heller, T., Hsieh, K., & Rimmer, J. Journal of Gerontological Social Work, 38(1/2), 161-178.
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- 520.022** **Dementia-related care decision-making in group homes for persons with intellectual disabilities**, (2002). Janicki, M.P., McCallion, P., & Dalton, A.J. Journal of Gerontological Social Work, 38(1/2), 179-195.
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- 520.019** **Evaluation of two self-report depression measures for adults with down syndrome**, (2002). Ailey, S.H., Marks, B., & Heller, T. The NADD BULLETIN, 5(4), 71-75.
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- 520.017** **Health characteristics and health services utilization in older adults with intellectual disability living in community residences**, (2002). Janicki, M., Davidson, P., Henderson, C., McCallion, P., Taets, J., Force, L., Sulkes, S., Frangenberg, E., & Ladrigan, P., Journal of Intellectual Disability Research, 46(4), 287-298.
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- 520.018** **Physical activities, dietary intake, and the insulin resistance syndrome in nondiabetic adults with mental retardation**, (2002). Draheim, C.C., Williams, D.P., & McCubbin, J.A. American Journal on Mental Retardation, 107(5), 361-375
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- 520.016** **Women with developmental disabilities: Health and aging**, (2002). Brown, A.A., & Gill, C.J. Current Women's Health Reports, 2, 219-225.
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- 520.014** **Differences in cardiovascular disease risk between nondiabetic adults with mental retardation with and without Down syndrome**, (2002). Draheim, C., McCubbin, J.A., & Williams, D.P. American Journal on Mental Retardation, 107(3), 201-211.
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- 520.024** **Determinants of exercise in adults with cerebral palsy**, (2002). Heller, T., Ying, G., Rimmer, J.H., & Marks, B.A. Public Health Nursing, 19(3), 223-231.
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- 520.025** **Health status of mothers of adults with intellectual disability**, (2001). Chen, S.C., Ryan-Henry, S., Heller, T., & Chen, E.H. Journal of Intellectual Disability Research, 45(5), 439-449.
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- 510.016** **A prospective study of menopause in women with Down syndrome**, (2001). Seltzer, G.B., Schupf, N., & Wu, H.S. Journal of Intellectual Disability Research, 45, 1-7.
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- 510.004** **Effect of menopause on cognitive performance in women with Down syndrome**, (2001). Patel, B.N., Seltzer, G.B., Wu, H.S., & Schupf, N. Neuroreport, 12(12), 2659-62.
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HEALTH PROMOTION

- 510.015 Risk factors for injuries and falls among adults with developmental disabilities**, (2001). Hsieh, K., Heller, T., & Miller, A.B. *Journal of Intellectual Disability Research*, 45, 76-82.
- 510.014 Prevalence of dementia and impact on intellectual disability services**, (2000). Janicki, M.P. & Dalton, A.J. *Mental Retardation*, 38, 277-289.
- 510.017 Overview of health issues of older women with intellectual disabilities** (2000). Gill, C.J., & Brown, A.A. *Physical & Occupational Therapy in Geriatrics, Special Issue- Aging and Developmental Disability: Current Research, Programming, and Practice Implications* (Eds.) Hammel, J. & Nochajski, S., Haworth Press, Inc., Vol 18 (1), 23-36.
- 500.019 Disabilities and health limitations**, (2000). Rimmer, J.H. In *Group fitness instructor manual. ACE's guide for fitness professionals* (226-246). San Diego: American Council on Exercise.
- 500.022 Effects of pacing vs. nonpacing on a one-mile walk test in adults with mental retardation**, (2000). Kunde, K. & Rimmer, J.H. *Adapted Physical Activity Quarterly*, 17, 413-420.
- 700.012 Impact of aging on persons with developmental disabilities**, (2000). Nochajski, S.M. *Physical and Occupational Therapy in Geriatrics*, Vol 18(1), 5-21.
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SELF ADVOCACY

Person-centered Planning for later life: Death and dying - A curriculum for adults with mental retardation, (2000). Sterns, H.L., Kennedy, E.A., & Sed, C.M.

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**, which emphasize 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 Instructor's Guide COST PER UNIT: \$35.00 for Guide and Notebook

ITEM NO: 100.015 Student Notebook (Additional Student Notebooks are \$12.50 each).

RRTCADD Disability Research Briefs

These research briefs summarize recent RRTCADD research and their findings. Individual briefs cost \$3.00 each or can be downloaded at no cost from the Advocacy page RRTCADD website www.rrtcadd.org.

ITEM NO: 100.024 Research Brief: **Use of State Institutions for People with Intellectual Disabilities in the United States**, (December 2005). Nelis, T. & Rizzolo, M. This brief reports the number of people with I/DD living in state-operated institutions in each state. It also reports the total number of people with I/DD living in different types of residential settings in the United States.

ITEM NO: 100.025 Research Brief #2: **Use of State Institutions for People with Intellectual Disabilities in Illinois** (January 2006). Nelis, T. & Rizzolo, M. This brief describes residential services in Illinois. It reports the number of people with I/DD in different types of residential settings and compares the cost of institutional care to living in small homes in the community.

Getting involved in research and training projects: A guide for persons with disabilities, (1996).

Heller, T., Miller, A., & Nelis. This is a guide to help persons with disabilities get involved in research and training activities.

ITEM NO: 100.003 COST PER UNIT: \$3.00 Available in PDF for no charge at www.rrtcadd.org.

Making choices as we age: A peer training program, (1996). Heller, T., Preston, L., Nelis, T., Brown, A., & Pederson, E.

This is a curriculum for training persons with disabilities and their co-trainers how to teach other adults with mental retardation about: choice making, rights and responsibilities, how to make healthy choices, 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 co-trainers 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.

ITEM NO: 100.004 COST PER UNIT: \$55.00 for Trainer's Guide and Coordinator's Guide

(Additional Trainer's Guides are \$25.00 each).

SELF ADVOCACY

Person-centered planning for later life: A curriculum for adults with mental retardation, (1993). Sutton, E., Heller, T., Sterns, H.L., Factor, A., & Miklos, S.

This research-based curriculum enables adults with mental retardation to actively plan for their later years 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.

**ITEM NO.: 100.002 COST PER UNIT: \$55.00 for Curriculum and Trainer's Guide
(Available in English, Dutch and German)**

Voices That Count Training Package (Videotape or DVD, Audio Cassette, Presenter's Guide, (1993), Pederson, E., & Chaikin, M.

Voices That Count prepares people with developmental disabilities to present to boards, committees and other decision-making groups about how to involve people with developmental disabilities. It empowers people to become part of the decision-making process that affects their own lives. Through *Voices That Count*, people with developmental disabilities will learn how to approach and present to professional and community organizations about the leadership roles and contributions people with developmental disabilities can make. Speakers will also learn how to give boards and committees ideas on how to recruit, support, and build partnerships with people with developmental disabilities.

ITEM NUMBER: 100.001 COST PER UNIT: \$85.00

JOURNAL ARTICLES: (\$3.25 EACH)

New! **100.026** Photovoice as Participatory Action Research Tool for Engaging People with Intellectual Disabilities in Research and Program Development, (2008). Jurkowski, J. Intellectual and Developmental Disabilities, 46 (1)1-11.

New! **100.028** 'Who Did What?': A Participatory Action Research Project to Increase Group Capacity for Advocacy, (2008). Garcia-Iriarte, E., Kramer, J.C., Kramer, J.M., Hammel, J. Journal of Applied Research in Intellectual Disabilities, 21.

New! **100.029** What does Participation Mean? An Insider Perspective from People with Disabilities, (2008). Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., and Rodriguez, E. Disability and Rehabilitation, 30 (19) 1445-1460.

100.027 Photovoice With Vulnerable Populations: Addressing Disparities in Health Promotion Among People With Intellectual Disabilities Research and Program Development, (2007). Jurkowski, J., Paul, A. Health Promotion Practice, 8(4) 358-365.

100.023 Nursing care resources for individuals with intellectual and developmental disabilities across the life span, (2003). Marks, B.A., Brown, A., Hahn, J.E., & Heller, T. The Nursing Clinics of North America: Intellectual and Developmental Disabilities 38(2), 373-393.

100.022 Promoting sexuality across the life span for individuals with intellectual and developmental disabilities, (2003). Ailey, S.A., Marks, B.A., Crisp, C., & Hahn, J.E. The Nursing Clinics of North America: Intellectual and Developmental Disabilities, 38(2), 229-252.

100.021 Leadership by people with disabilities in self-determination systems change, (2002). Powers, L.E., Ward, N., Ferris, L., Nelis, T., Ward, M., Wieck, C., & Heller, T. Journal of Disability Policy Studies, 13(2), 125-133.

100.020 Building community coalitions with people with disabilities and their families: An empowerment approach, (2001). Keys, C.B., & Factor, A.R. Journal of Prevention & Intervention in the Community, 21(2), 91-112.

100.016 Later-life planning: Promoting knowledge of options and choice-making, (2000). Heller, T., Miller, A., Hsieh, K., & Sterns, H. Mental Retardation, 38(5), 395-406.

CAREGIVING ISSUES

Revised 2nd Edition **The Future is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities**, (2009). Debrine, E., Caldwell, J., Factor, A., Heller, T., Keiling, K., & Kramer, J.

This curriculum equips families and their adult relative with a disability with the communication skills and information to jointly plan for the future. Participants learn how to overcome the emotional and systematic barriers to planning with the support of peer mentors who have made plans. They prepare a letter of intent that lays out their dreams for the future and identifies the steps required to transform this dream into a reality. This state-of-the-art approach to future planning was developed, implemented and evaluated by the RRTCADD. It is an excellent resource for agencies, family organizations and advocacy groups. **The Future is Now** received a National Alliance for Caregiving 2008 innovative program award. The revised second edition broadens the training's focus to include adult siblings without disabilities in the planning process and contains an updated and expanded resource list. It comes with a CD-ROM so that users can easily replicate copies of handouts for class exercises and homework assignments, English and Spanish versions of the letter of intent, and assessment tools.

ITEM NO: 100.018 **COST PER UNIT: \$70.00 (Softcover)**

Involvement of Adult Siblings of People with Developmental Disabilities in Future Planning. (June 2006). Kramer, J. & Heller, T. Disability Research Brief: Institute on Disability and Human Development.

Little is known about the role adult siblings play in planning for the future care of their sibling with a developmental disability. This research brief presents the results of a sibling survey to find out the extent siblings are involved in future planning and designated as the future caregiver, the resources they need to assume these responsibilities, and their concerns for the future.

ITEM NO.: 330.005 **COST PER UNIT: \$3.00**
Can be downloaded at no charge from: www.rrtcadd.org

Sibling Connections Newsletter, (2005, 2004). Kramer, J. & Heller, T., RRTC on Aging with Developmental Disabilities.

RRTCADD has started the Sibling Connections newsletter as a resource for siblings who are interested in advocacy and care issues for their brothers and sisters with disabilities. To learn more about this initiative, visit the sibling connections homepage on the RRTCADD website.

ITEM NO.: 330.004 **COST PER UNIT: \$3.25**
Can be downloaded at no charge from: www.rrtcadd.org.

Sibling Leadership Network Update. (2007), Kramer, J., & Heller, T.

Highlights of the RRTCADD's first Sibling Leadership Conference for siblings of people with disabilities held on November 9-10, 2007 at Washington, D.C. The conference featured over 80 brothers and sisters of individuals with intellectual disabilities.

ITEM NO.: 300.041 **COST PER UNIT: \$3.25**

Family handbook on future planning, (2003). Davis, Sharon, (Ed.). Produced by The Arc of the United States and the RRTC on Aging with Developmental Disabilities.

This guide helps families take the initial steps to address the future personal, legal, and financial needs of their sons or daughters with intellectual and developmental disabilities. It teaches families how to review and inventory their relative's needs and strengths, determine what the plan should include, and locate qualified professionals and resources to finalize the plan. It is an update of The Arc's 1991 handbook on future planning and the 1989 publication *How to Provide for Their Future*.

ITEM NO.: 300.011 **COST PER UNIT: No charge.**
View online and download at the RRTC Website: www.rrtcadd.org

CAREGIVING ISSUES

Future planning resource guide for families and adults with developmental disabilities in Illinois, (2006 rev.). Caldwell, J., Lopez, E., DeBrine, E., Factor, A., Heller, T., & Ennis, D.

This updated guide helps families navigate the maze of adult services and supports for individuals with developmental disabilities. It responds to families' need for a centralized source of information that describes adult services and how to access them. Content includes an overview of the service system and information on legal and financial planning, vocational and residential services, community supports, recreation and leisure opportunities, transportation, and advocacy. Information is in a user-friendly, question-and-answer format that was recommended by families. The guide is a template that other communities can follow in providing information on local services. **Also available in Spanish!**

ITEM NO: 100.019 **COST PER UNIT: \$15.00**
SPANISH VERSION ITEM NUMBER: 100.S19
View online at: www.rrtcadd.org and print at no cost

Adolescents and adults with autism: Recommended resources from families, Report #4. (2002), Krauss, M.W., Seltzer, M.M., Greenberg, R., Orsmond, G.I., & Magana, S.

This report contains the books, videos, and internet web sites that helped families learn more about their son or daughter's autism spectrum disorder. Families recommended these resources in a study of more than 400 parents caring for a child with autism spectrum disorder.

ITEM NO: 530.004 **COST PER UNIT: \$5.00**
Can be downloaded at no charge from: www.rrtcadd.org.

Las experiencias compartidas de familias Latinas de adolescentes y adultos con autismo / Shared experiences of Latino families of adolescents and adults with autism (Adolescentes y adultos con autismo un estudio de cuidado familiar proyecto Latino). (2003), Magana, S., Seltzer, M.M. & Krauss, M.W.

This bilingual report presents the challenges and rewards of caregiving expressed by Latino families who were part of a national study of families caring for adolescent and adult sons or daughters with autism. Families share their thoughts about their children living at home and away from home, their perspectives on caregiving, how their lives have changed, and what they have learned from this experience.

ITEM NO: 300.028 **COST PER UNIT: \$5.00**
Can be downloaded at no charge from: www.rrtcadd.org.

Adolescents and adults with autism: Reflections from adult siblings who have a brother or sister with autism spectrum disorder, Report #3. (2002), Krauss, M.W., Seltzer, M.M., Greenberg, R., Orsmond, G.I., & Magana, S.

This report presents siblings' perspectives on having a brother or sister with autism. It is based on a study of caregiving that included more than 400 families. Quotes from more than 200 adult siblings provide insight into their experiences over the life course. Topics include sibling relationships, community acceptance, positive and negative experiences of having a sibling with a disability, future expectations, and advice to parents and to teenage siblings.

ITEM NO: 530.003 **COST PER UNIT: \$5.00**
Can be downloaded at no charge from: www.rrtcadd.org.

CAREGIVING ISSUES

Adolescents and adults with autism, Report #1: A book of quotes: Shared experiences of families of adolescents and adults with autism, (2002). Seltzer, M.M., Krauss, M.W., Greenberg, J.S., Leavitt, L., Magana, S., Orsmond, G.I.

This report is based on interviews with more than 400 parents caring for a son or daughter with autism. This is the largest federally funded study of these families conducted to date. The thoughts and feelings these parents share express the extraordinary wisdom, energy, struggle, and triumphs associated with this caregiving experience.

ITEM NO: 530.001 **COST PER UNIT: \$5.00**
Can be downloaded at no charge from: www.rrtcadd.org.

Adolescents and adults with autism, Report #2: A profile of adolescents and adults with autism spectrum disorders, (2002). Seltzer, M.M., Krauss, M.W., Greenberg, J.S., Leavitt, L., Magana, S., Orsmond, G.I.

This report presents the objectives, methodology, and initial findings of the first large-scale research study of 405 adolescents and adults with autism and spectrum disorders (ASD) and their families. It contains data on diagnosis, symptoms and behaviors, services and treatments, and participation in social and recreation activities. The authors compare these data to the research findings to date.

ITEM NO: 530.002 **COST PER UNIT: \$5.00**
Can be downloaded at no charge from: www.rrtcadd.org.

Grandparents raising grandchildren with developmental disabilities, (2002). Heller, T., & Ganguly, R.

This paper examines the demographics of grandparent caregivers of children and adults with developmental disabilities, their reasons for assuming this role, their needs, concerns and challenges. Additionally it reviews supportive interventions for this population and implications for the aging network in designing and coordinating services as part of the National Family Caregiver Support Program. **Reproduced with permission of the U.S. Administration on Aging and The Lewin Group.**

ITEM NO: 310.012 **COST PER UNIT: \$7.00**
Can be downloaded at no charge from: www.rrtcadd.org.

Pooled trust programs for people with disabilities: A guide for families, (2001), by The Arc of the United States.

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's question-and-answer format provides a clear understanding of pooled trust programs and serves as a guide to help families and professionals evaluate this future planning option. It 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.

ITEM NO: 300.005 **COST PER UNIT: \$7.00 for a bound copy**
Can be downloaded at no charge from: www.rrtcadd.org.

Aging family caregivers: Needs and policy concerns, (2000). Heller, T. **Family Support Policy Brief #3**. National Center for Family Support.

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.

ITEM NO.: 310.013 **COST PER UNIT: \$3.00**

CAREGIVING ISSUES

New! Family Support Interventions for Families of Adults with Intellectual and Developmental Disabilities. Heller, T. & Schindler, A. (2009) In L. G. Masters and M.M. Seltzer (Eds.), *International review of research in mental retardation*, Vol. 37, (pp. 299-333). Oxford, U.K.: Elsevier Ltd. Email the Clearinghouse (www.rrtcadd.org) to receive an electronic version of this chapter at no cost. To order the hardcover book (\$185.00 US), contact Elsevier at <http://www.elsevierdirect.com/product.jsp?isbn=9780123744661&dmnum=CWS1> .

ITEM NO: 300.046

JOURNAL ARTICLES: (\$3.25 EACH)....

New! Health Profile of Aging Family Caregivers Supporting Adults With Intellectual and Developmental Disabilities. (2009). Yamaki, K., Hsieh, K & Heller, T. *Intellectual and Developmental Disabilities*, 47(6), 425-435.

New! Involvement of Adult Siblings of Persons with Developmental Disabilities in Future Planning, (2009). Heller, T. & Kramer, J. *Intellectual and Developmental Disabilities*, 47, 208-219.

New! Adolescents and Adults with Autism with and without Co-morbid Psychiatric Disorders: Differences in Maternal Well-Being. (2008). Kring, S.R., Greenberg, J.S. and Seltzer, M.M. *Journal of Mental Health Research in Intellectual Disabilities* 1(2). 53-74

New! Family Support and intergenerational Caregiving: Report of the State of the Science in Aging with Developmental Disabilities Conference: (June 2008). Heller, T., Factor, A. *Disability and Health Journal*, 1, 131-135.

New! Health Behaviors, Service Utilization, and Access to Care Among Older Mothers of Color Who Have Children with Developmental Disabilities. (2008). Magaña, S., Smith, M.J. *Journal of Intellectual and Developmental Disabilities*, 46(4). 267-280.

New! Health and Access to Health Care of Female Family Caregivers of Adults with Developmental Disabilities. (2008). Caldwell, J. *Journal of Disability Policy Studies*, 19(2). 68-79.

Longitudinal Outcomes of a Consumer-Directed Program Supporting Adults with Developmental Disabilities and Their Families. (2007). Caldwell, J., Heller, T. *Journal of Intellectual and Developmental Disabilities* 45(3). 161-173.

Depressive Symptoms in Adults with Mild to Moderate Intellectual Disability and Their Relation to Maternal Well Being. (2006). Esbensen, J., Anna, Seltzer-Mailick, Marsha, Greenberg, J. *Journal of Policy and Practice in Intellectual Disabilities* 3(4). 229.

Consumer-Directed Supports: Economic, Health, and Social Outcomes for Families. (2006) Caldwell, J. *Mental Retardation*, 44(6). 405-417.

Supporting Aging Caregivers and Adults with Developmental Disabilities in Future Planning. (2006). Heller, T., Caldwell, J. *Mental Retardation*, 44(3). 189-202.

Bidirectional Effects of Expressed Emotion and Behavior Problems and Symptoms in Adolescents and Adults With Autism. (2006). Greenberg, J. S., Seltzer, M. M., Hong, J. *American Journal of Mental Retardation*, 111(4), 229-249.

Health Outcomes of Midlife and Older Latina and Black American Mothers of Children With Developmental Disabilities. (2006). Magaña, S., Smith, M. J. *Mental Retardation*, 44(3). 224-234.

Mother-child relationship quality among adolescents and adults with autism. (2006). Orsmond, G.I., Seltzer, M.M., Greenberg, J.S., & Krauss, M.W. *American Journal on Mental Retardation*, 111(2), 121-137.

Life course studies of siblings of individuals with developmental disabilities. (2005). Seltzer, M. M., Greenburg, J. S., Orsmond, G. I., & Lounds, J. *Mental Retardation*, 43(5), 354-359.

Life course impacts of mild intellectual deficits. (2005). Seltzer, M.M., Floyd, F., Greenberg, J.S., & others. *American Journal on Mental Retardation*, 110(6), 451-468.

Brief Research Report: Impact of a Consumer-Directed Family Support Program on Reduced Out-of-Home Institutional Placement, (2005). Heller, T., Caldwell, J. *Journal of Policy and Practice in Intellectual Disabilities*, 2(1), 63-65.

CAREGIVING ISSUES

- 300.031** **Controlled evaluation of support groups for grandparent caregivers of children with developmental disabilities and delays.** (2004). McCallion, P., Janicki, P.M., & Kolomer, S.R. American Journal on Mental Retardation, 109(5), 352-361.
- 300.030** **Cultural context of care giving: Differences in depression between Puerto Rican and non-Latina white mothers of adults with mental retardation,** (2004). Krauss, M.K., Magana, S., & Seltzer, M.M. Mental Retardation, 42(1), 1-11.
- 300.029** **Management of respite and personal assistance services in a consumer-directed family support program,** (2003). Caldwell, J., & Heller, T. Journal of Intellectual Disability Research, 47(4/5), 352-366.
- 300.026** **Service utilization patterns of adults with intellectual disabilities: A Comparison of Puerto Rican and Non-Latino White Families,** (2002). Magana, S., Seltzer, M.M., and Krauss, M.W. Journal of Gerontological Social Work, 37(3-4), 65-86.
- 300.027** **African-American grandmother carers of children with disabilities: Predictors of depressive symptoms,** (2002). Kolomer, S.R., McCallion, P., and Janicki, M.P. Journal of Gerontological Social Work, 37(3-4), 45-64.
- 300.023** **Quality of life of adults with mental retardation/ developmental disabilities who live with family,** (2001). Seltzer, M.M., and Krauss, M.W. Mental Retardation and Developmental Disabilities Research Review, 7, 105-114.
- 300.024** **RRTC collaborates with Chicago Arc on family future planning project,** (2000). Heller, T., Caldwell, J., & DeBrine, E. ADD/Vantage, 11(2), 1,12,13,15.
- 300.025** **Innovative project supports later-life planning for adults and their aging family caregivers,** (2001). Heller, T., & Caldwell, J. Maximizing Human Potential, 8(3), 4-5.
- 300.021** **Continuity or discontinuity of family involvement following residential transitions of adults with mental retardation,** (2001). Seltzer, M.M., Krauss, M.W., Hong, J., & Orsmond, G.I. Mental Retardation, 39, 181-194.
- 300.022** **Change in social support and psychological well-being: A longitudinal study of aging mothers of adults with mental retardation,** (2001). Hong, J., Seltzer, M.M., & Krauss, M.W. Family Relations, 50, 154-164.
- 300.019** **Families of adolescents and adults with autism: Uncharted territory,** (2001). Seltzer, M.M., Krauss, M.W., Orsmond, G.I., & Vestal, C. International Review of Research in Mental Retardation, 23, 267-294.
- 300.018** **Supporting adults with intellectual disabilities and their families: A literature review,** (2000). Heller, T. Physical & Occupational Therapy in Geriatrics, Special Issue- Aging and Developmental Disability: Current Research, Programming, and Practice Implications, The Haworth Press, Vol 18 (1), 59-73.
- 300.017** **Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship,**(2000). Orsmond, G. & Seltzer, M.M. American Journal of Mental Retardation, 105(6), 486-508.
- 300.015** **Grandparents as supports to mothers of persons with intellectual disability,** (2000). Heller, T., Hsieh, K., & Rowitz, L. Journal of Gerontological Social Work, 33, 23-34.
- 310.015** **Grandparent caregivers I: Characteristics of the grandparents and the children with disabilities for whom they care,** (2000). Janicki, M.P., McCallion, P., Grant-Griffin, L., & Kolomer, S.R. Journal of Gerontological Social Work, 33(3), 35-55.
- 310.014** **Grandparent caregivers II: Service needs and service provision issues,** (2000). McCallion, P., Janicki, M.P., Grant-Griffin, L., & Kolomer, S.R. Journal of Gerontological Social Work, 33(3), 63-90.
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POLICY/SERVICE DELIVERY

NEW! Recommendations for Research, Advocacy and Supports Relating to Siblings of People with Developmental Disabilities. (2008). Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., & Dufresne, D.

This white paper was developed by The Sibling Leadership Network (SLN), a national organization that provides adult siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. The SLN was founded by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, the Nisonger Center at The Ohio State University, the Sibling Support Project, and the Vanderbilt Kennedy Center for Excellence in Developmental Disabilities.

ITEM NO: 600.035

COST PER UNIT: \$10.00

It can be downloaded at no charge from the RRTCADD website at www.rrtcadd.org

Family Support 360: Empowering a Community. Executive Summary. (2007). Heller, T., Connolly, K. & Lacey, B. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.

This report describes the development and outcomes of a one-stop center that meets the information and support needs of unserved and under-served Chicago area Latino families of children and adults with developmental disabilities. The center is a unique family driven model that demonstrates how advocacy training enabled these families to obtain long-term funding to sustain the center's operations.

ITEM NO.: 600.028

Can be downloaded at no charge from <http://www.idhd.org/>

International Perspectives. (2007). Emerson, E., Fujiura, G.T., & Hatton, C. 593-613.

This chapter is in the Handbook on Developmental Disabilities, edited by S. L. Odom, R.H. Horner, M. Snell, & J. Blacher, which reviews the breadth of current knowledge in the field.

ISBN: 978-1-60623-248-4

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Aiding Older Caregivers of Persons with Intellectual and Developmental Disabilities: A Tool Kit for State and Local Aging Agencies. Baxley, D. L., Janicki, M. P., McCallion, P., & Zendell, A., 2005.

This technical assistance manual explains how states can develop aging and developmental disability service network partnerships to better address the needs of older adults with I/DD and the families. It is based on the outcomes of a three-year AoA National Family Caregiver Support Program demonstration the developed and conducted collaboration-building workshops in 33 states. The project was undertaken by The Arc of the United States in collaboration with the Center of Intellectual Disabilities, University at Albany and the Rehabilitation Research and Training Center of Aging with Developmental Disabilities, University of Illinois at Chicago.

Can be downloaded from our publication list for no charge at www.rrtcadd.org

ITEM NO.: 630.003

COST PER UNIT: \$15.00

POLICY/SERVICE DELIVERY

Aging with a Developmental Disability: 2005 White House Conference on Aging Listening Session Testimony, (December 8, 2005). Factor, A.

This brief identifies the issues that aging adults with I/DD and their families face, indicating why their service and support needs should be included in the 2005 White House Conference on Aging Agenda.

ITEM NO.: 610.012 COST PER UNIT: \$5.00

Can be downloaded from our publication list for no charge at www.rrtcadd.org.

Public spending for developmental disabilities in the United States: An historical-comparative perspective. Braddock, D., Rizzolo, M.C., Hemp, R., & Parish, S. (2004). In R.J. Stancliffe and K.C. Lakin (Eds.) Cost and Outcomes of Community Services for people with intellectual disabilities. Baltimore: Brookes Publishing Company.

This book provides a comprehensive analysis of the cost of community services for individuals with I/DD. It examines the criteria used to allocate funds, differences in outcomes and costs for various service models, and policy considerations in developing individualized services within state systems.

ISBN 1-55766-718-7 Cost \$34.95

Order directly from the publishers website:

<http://www.brookespublishing.com> or 1-800-638-3775

DD data brief: Gender, age, and disability differences in functional limitations for non-institutionalized adults in the NHIS-D, (Vol. 6, No.1) January, 2004

Doljanac, R., Larson, S., & Lakin, C. (Eds.), Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

This DD Data Brief summarizes findings from the 1994-95 National Health Interview Survey on Disability. This DD Data Brief describes gender, age, and disability differences in functional limitations for non-institutionalized adults.

Order directly from University of Minnesota at 612-624-4512, <http://rtc.umn.edu/nhis> or by email: publications@icimail.umn.edu.

DD data brief: Service use by and needs of adults with functional limitations or ID/DD in the NHIS-D: Difference by age, gender, and disability, (Vol. 5, No.2), (Dec. 2003). Larson, S., Lakin, C., & Huang, J. (Eds.), Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

This DD Data Brief summarizes findings from the 1994-95 National Health Interview Survey on Disability. It supplements the April 2001 MR/DD Data Brief on characteristics of and service use by persons with MR/DD living in their own homes or with family members. This brief examines how service use and needs vary by age, gender, and (persons with intellectual and/or developmental disabilities [ID/DD] versus persons with one or more substantial functional limitations who do not meet the criteria of having ID/DD).

Order directly from University of Minnesota at 612-624-4512, <http://rtc.umn.edu/nhis> or by email: publications@icimail.umn.edu.

POLICY/SERVICE DELIVERY

Information about the Preparing Community Agencies for Adults Affected by Dementia Project (PCAD Project) (2005). Janicki, M., Dalton, A., McCallion, P., Baxley, D., & Zendell, A.

A preliminary report about the NIDRR funded research project on how community agencies adapt their services for adults with intellectual disabilities.

ITEM NO: 610.010 COST PER UNIT: \$3.75 per paper copy. Can be downloaded at no charge at www.rrtcadd.org from the **Highlighted Topics page Alzheimer's resource list.**

American Journal on Mental Retardation, Special Issue Aging: Family and Service System Supports, September 2004, Volume 109, Issue 5

This issue of the American Journal on Mental Retardation addresses the effects of aging on families caring for persons with intellectual disabilities in Australia, the United States, Israel, and Ireland and discusses the impact on their health and social service systems. Tamar Heller, director of the RRTC on Aging with Developmental Disabilities, is guest editor.

Coordinating systems serving carers of children and adults with developmental disabilities, (2002). Janicki, M.

Aging adults with intellectual and developmental disabilities face many of the same challenges as other aging adults. Physical aging, social isolation, disengagement from work or activities and challenges of retirement are issues that must be faced by aging adults with cognitive disabilities in addition to the possibility of needing additional assistance from carers to determine their future. This report gives an overview of common definitions, care and support issues, and how systems can partner in the delivery of community support networks. **Reproduced with permission of the U.S. Administration on Aging and The Lewin Group.**

ITEM NO.: 600.006 COST PER UNIT: \$7.00
Can be downloaded at no charge from: www.rrtcadd.org .

DD data brief: Health insurance coverage and health care experiences of persons with disabilities in the NHIS-D, (Vol. 5, No.1), (May 2003). Anderson, L., Larson, S., Lakin, C., & Kwak, N. (Eds.), Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.

This DD Data Brief describes the experiences with public and private health insurance coverage for people with functional limitations, people with I/DD, and people who do not have I/DD or functional limitations. This Brief also examines the variations in these outcomes by gender and age.

Order directly from University of Minnesota at 612-624-4512, <http://rtc.umn.edu/nhis> or by email: publications@icimail.umn.edu.

Community supports for aging adults with lifelong disabilities, (2000). Janicki, M. & Ansello, E. (Eds.) Baltimore: Brookes Publishing.

This book provides practical approaches that enable older adults to remain in their homes and communities as they age. It draws on field-tested experiences and situations that can be applied to most settings. Topics include: financing services for older adults, collaboration between community agencies, health promotion, and designing age-related services.

ISBN: 1-55766-462-5 Cost per unit: \$58.00
Order directly from the publisher at: www.brookespublishing.com/ or 1-800-638-3775.

POLICY/SERVICE DELIVERY

RRTCADD Disability Research Briefs

This new series of briefs summarize recently completed RRTCADD research projects and their findings. Individual briefs cost \$3.00 or can be downloaded at no cost from the RRTCADD website www.rrtcadd.org

ITEM NO: 600.025 Predictors of use of nursing homes and state institutions for persons with DD (2004). Rizzolo, M.K. This RRTCADD research brief explains the wide variation in states' use of nursing homes and state institutions compared to community residential options for individuals with developmental disabilities. It also compares the health characteristics of nursing home residents with and without developmental disabilities.

ITEM NO: 600.024 Disability Research Brief: Evaluation of a consumer directed program: Illinois (2004). Heller, T. & Caldwell, J. This research brief presents the outcomes of Illinois innovative consumer-directed Home Based Support Services Program for adults with developmental disabilities and their families. It compares participants and non-participants on service use and satisfaction, community involvement, and the need for out-of-home residential placements.

ITEM NO. 600.026 Supporting aging caregivers and adults with developmental disabilities in future planning (2004). Heller, T., Caldwell, J. and Factor, A. This brief evaluates the outcomes of an innovative training curriculum that equips adults with disabilities and their families with the communication skills and information to jointly plan for the future with the support of peer mentors who have already made plans.

Promoting healthy aging, family support, and age-friendly communities for persons with developmental disabilities: Report of the 2001 Invitational Research Symposium on Aging with Developmental Disabilities, (2002). Heller, T., Janicki, M, P., Hammel, J., & Factor, A.R.

This report summarizes the research to date and presents recommendations for future research, progressive policies, and innovative intervention to promote healthy aging, support aging adults and their families, and create age-friendly communities. These recommendations coalesce the thinking of the 100 plus international researchers, service providers, families and persons with disabilities who participated in the conference.

ITEM NO.: 600.017 COST PER UNIT: \$10.00 per bound copy.
Can be downloaded at no charge from: www.rrtcadd.org

Value-based human resources management, (2000). Henry, D.B., Keys, C.B., & Factor, A.R., In M. Janicki & E. Ansello (Eds.), Community supports for aging adults with lifelong disabilities. (271-286) Baltimore: Brookes Publishing.

Staff in health care and human services organizations that serve the general population may not have the skills to communicate with older adults with intellectual disabilities. This may lead to an inaccurate assessment of the individual's needs and to an intervention which isn't appropriate to his/her situation. This chapter explains how organizations can develop and implement management standards based on the values of empowerment, independence, choice, and autonomy to better serve older adults with intellectual disabilities and their families.

ISBN: 1-55766-462-5 COST PER UNIT: \$58.00
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POLICY/SERVICE DELIVERY

Physical & Occupational Therapy in Geriatrics, Special Issue-Aging and Developmental Disabilities: Current Research, Programming and Practice Implications. (2000). Hammel, Joy, & Nochajski, Susan M. The Haworth Press, Vol 18 (1).

ITEM NO.: 800.009 COST PER UNIT: \$60.00

ISSN: 0270-3181

Order directly from the publisher at: www.HaworthPress.com or call 1-800-429-6784.

JOURNAL ARTICLES: (\$3.25 EACH)....

The demography of intellectual disabilities: What the beans tell us. (2007). Fujiura, G.T.
600.033 *Insight*, 1 (4), 12-20.

New! Residential Characteristics, Social Factors, and Mortality Among Adults With Intellectual Disabilities: Transitions Out of Nursing Homes. (2009). Caldwell, J. *Journal of Intellectual and Developmental Disabilities*, 47(6), 447-465.

600.032 Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program, (October 2007). Caldwell, J., *Disability & Society*, 22 (6), 549-562.

600.027 Cultural Competence Revisited: Nursing Students with Disabilities, (February 2007). Marks, B. *Journal of Nursing Education* 46(2).

600.029 Aging Family Caregivers: Policies and Practices, (June 2007). Heller, T., Caldwell, J., Factor, A. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 136-142.

600.030 Emerging Policy Challenges in Intellectual Disabilities, (June 2007). Fujiura, G., Parish, S. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 188-194.

600.031 Policies that Shape the Intellectual Disabilities Service System, (June 2007). Fujiura, G., Parish, S. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, iii- iv.

600.034 Lessons drawn from the critique of the Hissom closure evaluation. (2006). Fujiura, G.T. *Mental Retardation* 44, 372-375.

630.011 Determinants of State Utilization of Public Institutions for Persons with Intellectual Disabilities in the United States, (2005). Rizzolo, M.C., Heller, T., Braddock, D. *Journal of Policy and Practice in Intellectual Disabilities*, 2(1), 60-62.

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