



# ADDVANTAGE

A newsletter about aging and developmental disabilities Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function Department of Disability and Human Development College of Applied Health Sciences

OLUME I, ISSUE 2

#### OCTOBER 2009

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### Welcome from the Director,

In this year of financial challenges to the world economy and to national and state budgets, we have to continue to advocate for support services for adults with intellectual and developmental disabilities (I/DD) and their families. We also need to continue to develop and implement practices that help improve the quality of life and health of these individuals and families.

One example of this type of initiative is the *Health Education for Latina Caregivers* intervention developed and being tested by Sandy Magana as part of the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD). This issue of the ADDvantage highlights this project and its potential for reducing depression among Latina mothers of adults with intellectual and developmental disabilities.

The RRTCADD is also continuing to revise and to present train-the trainer workshops in the "Future is Now" curriculum, which helps individuals with I/DD and their families jointly develop plans for the future. Most recently, we conducted these trainings for the Rosalynn Carter Institute in Georgia.

We are also pleased to announce new publications, including two upcoming books, *Health* Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities and Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Program (Marks, Sisirak, & Heller, in press), which are a product of both considerable research and practical applications in the community. These books should be helpful to individuals and agencies interested in developing and implementing health promotion programs for adults with I/DD.

Please feel free to provide us feedback on our newsletter and let us know of resources and events that we can share in future issues. You can send your comments to Alan Factor, Ph.D, the RRTCADD Associate Director for Training and Dissemination and the ADDvantage editor, at afactor@uic.edu.

Sincerely,

Tamor Heller

### Tamar Heller, Ph.D



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### **RRTCADD Research Activities**

### Health Education for Latina Caregivers of Adults

RRTCADD researcher Sandy Magaña is undertaking an innovative education intervention to improve the health and psychological well-being of older Latina mothers caring for their child with intellectual and related developmental disabilities (I/DD). The need for a health education intervention became apparent from Magaña's previous RRTCADD research, which identified health disparities among older Black and Latina caregivers. It was the first study to examine the health status of caregivers of color within the environmental and ecological context of their communities. Magaña analyzed data from the 2000 National Health Interview Survey to compare 162 Latina and Black American mothers age 40 and older co-residing with a child with I/DD to 2,754 of their age peers who were not caring for a child with I/DD at home. The findings revealed that Latina caregivers ages 40-54 were twice as likely to report a higher rate of depressive symptoms even though their physical health did not differ from non-caregivers. Older Latina caregivers (age 55+) were 5.1 times more likely to report heart problems and 3.8 times more likely to activity limitations due to arthritis and 4.0 times more likely to experience activity limitations due to arthritis and 4.0 times more likely to experience activity limitations due to diabetes than older Black American noncaregivers.<sup>1</sup>

Magana's current project employs the *promotora* model of recruiting and training women from the Latino community as lay health educators to mothers caring for adults with I/DD. . This intervention is unique because the lay health educators are not only members of the Latino community, but they are also mothers of a child with I/DD themselves. These *promotoras* understand the challenges of caring for one's own health while being the primary caregiver of a child with I/DD within the broader matriarchal role defined by Latino culture. They can readily relate to project participants, and mothers consider them credible providers of information and strategies to reduce stress and fit healthy behaviors into their lives. Addressing these mothers' health and well-being indirectly helps the person with I/DD by making sure they are healthy, happy, and able to continue to provide support.

*Promotoras* schedule nine visits with individual mothers in their home. Health education content addresses the importance of caring for oneself, health care visits, wellness activities, nutrition, exercise, reducing stress, social support and sustaining growth. Each topic is discussed in terms of its relevance to enhancing the mother's effectiveness as the primary caregiver of her child with a disability.

*Promotoras* are recruited by asking agencies and support groups that serve Latino families of children with I/DD to identify mothers who emerged as parent leaders. Mothers who are interested in the project attend three 4-hour group training sessions to learn the health education content. *Promotoras* completed pre and post-tests prior to and after completing the training to assess their skill and knowledge gains. To date, ten *promotoras* have been trained in Madison and Milwaukee, Wisconsin and have provided health education to thirteen mothers.

Preliminary findings for this pilot are very promising based on comparisons of pre and post-training survey data for both *promotoras* and the mothers they trained Figure 1 indicates the mothers who completed the training reported a significant decrease in depressive symptoms and a higher degree of positive self care, nutrition, and exercise behaviors at the end of the intervention.



Continued on p.4

### **RRTCADD Research Activities**

### **RRTCADD Research Participants Needed....**

The RRTCADD is recruiting individuals with intellectual disabilities to participate in two of its studies on health issues. We are seeking individuals 18 and older in the United States with intellectual disabilities to participate in our **Longitudinal Health and Intellectual Disability Study (LHIDS)** so we can learn how certain health behaviors such as diet and physical activity are related to their health. The survey, which takes about 30 minutes to complete, will be conducted once per year for five years. It includes questions about current health problems, participation in physical activity, alcohol consumption, diet, and oral hygiene. Respondents will receive a \$5.00 gift card for each survey they complete. Individuals who need assistance with the survey can ask a staff person or family member to assist them or to answer the questions on their behalf. Surveys can be completed by mail or online. To register for the study, or to learn more about the study, please contact Benjamin Graham, the project coordinator, at (312) 355-1396 or bcgraham@uic.edu.

The RRTCADD is also seeking collaboration sites to participate in its study of **Neurodevelopmental Conditions and Lifespan Health Outcomes** to identify trends in age-related health decline including biomarkers associated with the onset of secondary conditions in adults with specific neurodevelopmental disabilities. Sites will be asked to collect data on a sample of the individuals they serve using Rochester Health Status Survey-IV (RHSS-IV), a 16-page questionnaire composed of four sections: 1) demographics, 2) general physical health, 3) medical conditions including lifetime prevalence, point prevalence (last 24 months), and incidence (last 3 months), and 4) health services utilization and health surveillance. If you or your program/center would be interested in collaborating with this project, by collecting data on even just a few subjects, the Principal Investigators would like to hear from you. If you are interested, or simply want more information, contact <u>Dr. Matthew</u> <u>Janicki</u> at <u>mjanicki@uic.edu</u>.

### Attendees at the Special Olympic International Grant Writing Workshop in Chicago

In its role as a Special Olympics International (SOI) Collaborating Research Center, the RRTCADD and SOI staff held a grant writing workshop for applicants intending to submit proposals for the SOI Health Promotion Community-Based Grants Program. These 1-year, \$20,000 grants are awarded to Special Olympics (SO) Programs to develop strong, sustainable health promotion partnerships at the local level. The grantwriting workshops, which were held March 12-13, 2009 at the University of Illinois at



Chicago were designed to help SO programs develop feasible, high-quality grant applications. Four SO Programs from Mauritius, Kenya, and the United States (Indiana and Minnesota) and their community partners participated in this 1.5 day workshop.

### **RRTCADD Research Activities**

### Health Education for Latina Caregivers of Adults (continued)

Figure 2 indicates the *promotoras* were good role models for the mothers because they had fewer depressive symptoms and higher positive health behaviors at baseline. Consequently, their post-training gains were not as great as the mothers because there was less room for improvement. All of the significant findings so far are quite remarkable because of the small sample sizes in this preliminary analysis.

#### Figure 2: Promotoras pre and post tests



The next stages of the project are to continue participant recruitment and program delivery in Milwaukee and to implement a large scale project in Chicago. In the Chicago study, Dr. Magaña plans to recruit three groups of participants: mothers who receive the home visits, mothers who receive training in a group and those who do not receive any training. This method will determine the relative effectiveness of the individual home visit modality. Because of the project's positive preliminary findings, United Way of Dane County is in discussions with Dr. Magaña about working with a community partner to sustain the project as a community service.

### Reference

Magaña, S. & Smith, M. Health outcomes of midlife and older Latina and Black American mothers of children with developmental disabilities. *Mental Retardation*, 2006; 44(3): 224-234.

## **RRTCADD** People

RRTCADD Researchers **Alan Factor, Ph.D**. and **Katie Keiling Arnold** have been invited by the Rosalynn Carter Institute for Caregiving to conduct a Train-the-Trainer Institute for *The Future is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities* on October 21 at its 2009 National Summit. The curriculum, which received a National Alliance for Caregiving 2008 Innovative Program Award, 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 systemic 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. The revised second edition broadens the training focus to include adult siblings without disabilities in the planning process and contains an updated and expanded resource list. For more information on the Summit visit <u>www.rcisummit09.org/conferencehome.html</u>, and for information on ordering The Future is Now visit the RRTCADD website <u>www.rrtcadd.org</u>.

## **RRTCADD** People

#### Maureen Arcand's Celebratory Milestone



On April 30, 2009 Maureen Arcand, a 16 year member of the RRTCADD Advocate Advisory Group, was honored at her 80<sup>th</sup> birthday celebration for her community activism and advocacy leadership over several decades for people with disabilities. Maureen, who lives in Madison, Wisconsin, served on the Dane County Board of Supervisors, co-founded the East Side Community Center, organized the Dane County Welfare Alliance, and continues to advocate for independent living services for people with disabilities. As co-facilitator of the RRTCADD Advocate Advisor meetings, Maureen guided the group's discussion of the Center's research and training activities and recruited individuals to work on specific projects.

Movin' Out, a Madison organization that provides affordable housing for people with disabilities, sponsored Maureen's party and presented her with the first Maureen Arcand Lifetime Achievement Award. The Dane County Board of Supervisors also passed a resolution honoring Maureen for her achieve-

ments. Over 250 people attended the celebration including Madison's mayor Dave Cieslewicz, Dane County director Kathleen Falk, Maureen's six children, and her grandchildren.

In congratulating Maureen, RRTCADD director Tamar Heller commended her research on aging and disability by noting "On her 70th birthday, Maureen declared 'I am out there and talking about it!' Now, on her 80<sup>th</sup>, she is *still* out there inspiring us!"

Visit <u>http://www.movin-out.org/documents/maureenarcand/Maureen\_presentation.pdf</u> for photos of her party.



The RRTCADD welcomes **William Owens, Jr.** as the newest member of its Advocate Advisory Group. William, a native Chicagoan, has been an active advocate for people with disabilities through ADAPT and Access Living. William attended his first Advocate Advisory Group meeting on April 23, 2009. He now has expanded his energy and self-advocacy efforts to the RRTCADD.

Photo—left to right: William Owens, Jr., veteran advisor Marvin Moss, and self-advocacy specialist Tia Nelis.

## **RRTCADD** People

**Joe Caldwell, Ph.D.**, former RRTCADD project director, was awarded a Public Policy Fellowship by the Joseph Kennedy Jr. Foundation. Joe is working on health care reform legislation with the staff of Senator Christopher Dodd (D-CT), who chairs the Subcommittee on Children and Families of the Senate Health, Education, Labor, and Pensions Committee. The Kennedy Foundation awards these fellowships to outstanding professionals working in the field of inclusive services and supports for people with mental retardation, intellectual and developmental disabilities.

**Tamar Heller**, RRTCADD Director, was awarded the 2009 Autism Ally for Public Policy Award by The Arc and The Autism Program of Illinois in April, 2009.

**Chitra Gurung**, RRTCADD Graduate Assistant on the Consumer Directed Supports research project, was awarded the 8<sup>th</sup>Annual Ann and Edward Page-El, MD Scholarship in May 2009.

**Katie Keiling**, RRTCADD researcher and **John Kramer**, Ph.D., former RRTCADD project director, were chosen as co-chairs of the National Sibling Leadership Network in February 2009.



**Beth Marks, Ph.D., R.N.,** (left) receives the Distinguished Alumnus Award from Andrea R. Lindell, Dean of the College of Nursing at the University of Cincinnati.

Beth Marks, RN, PhD, RRTCADD Associate Director for Research, received the distinguished Alumni Award from the University of Cincinnati, College of Nursing for her leadership in developmental disabilities and rehabilitation research. Beth's RRTCADD research focus includes developing and evaluating staff training programs to maximize the health and function of adults with I/DD through health promotion, health literacy, and health advocacy. Two books based on her research, Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities and Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Program, will be available from Brookes Publishing Company this fall. Aside from her RRRTC commitments, Dr. Marks is an international leader in incorporating disability into nursing curricula and is a strong advocate for expanding career opportunities for nurses with disabilities. She co-produced the documentary Open the Door, Get 'Em a Locker: Educating Nursing Students with Disabilities that was released in February.

### **RRTCADD Researchers Keynote Hong Kong**

### Conference

RRTCADD researchers Kelly Hsieh, Ph.D. (3<sup>rd</sup> from right) and Matthew Janicki, Ph.D. (3<sup>rd</sup> from left) were invited presenters at the Seminar on Aging of People with Intellectual Disabilities held in Hong Kong on June 29-30. Janicki presented an overview of aging and related issues and Hsieh discussed aging well for adults with I/DD to an overflow audience of 320 service providers, clinicians, health care professionals, parents and consumers. The seminar was sponsored



by the International Association for the Scientific Study of Intellectual Disabilities Academy on Education, Teaching and Research. Local hosts were the Hong Kong Joint Council for People with Disabilities and the Hong Kong Council of Social Service. Hsieh and Janicki also provided technical assistance to the local aging work group on services and supports to address later life changes in health and function.

## **New RRTCADD Publications**

Publications are available from the RRTCADD Clearinghouse on Aging and Developmental Disabilities, which is a resource for information and products related to aging with developmental disabilities.

• Revised 2<sup>nd</sup> 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.

**The Future is Now** received a National Alliance for Caregiving 2008 innovative program award. The 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 them 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 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: \$70.00** 

- Involvement of Adult Siblings of Persons with Developmental Disabilities in Future Planning, (2009). Heller T. & Kramer, J. Intellectual and Developmental Disabilities, 47, 208-219. Item No: 300.045 Cost: \$3.25
- 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 <u>www.rrtcadd.org</u>

• Photovoice as Participatory Action Research Tool for Engaging People with Intellectual Disabilities in Research and Program Development, (2008). Jurkowski, J. <u>Intellectual and Developmental Disabilities</u> U, 46 (1)1-11

Item No: 100.026 Cost: \$3.25.

• 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. <u>Disability and Rehabilitation</u>, 30 (19) 1445-1460.

Item No: 100.029 Cost: \$3.25

• 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

Item No: 300.044 Cost: \$3.25

## **New RRTCADD Publications**

**To order RRTCADD products:** Make checks, money orders, or purchase orders payable to the Institute on Disability and Human Development, Fed. I.D. # 37-6000511, and mail to:

The Clearinghouse on Aging and Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago, 1640 West Roosevelt Road, Chicago, Illinois 60608-6904

For more information, call Erika Magallanes: Local: (312) 413-1520 Local TTY: (312) 413-0453 Fax: (312) 996-6942 Outside Chicago: (800) 996-8845 (V); (800) 526-0844 (TTY)

Visit us on the web at <u>www.rrtcadd.org</u>

### Soon to be available from Brookes Publishing Company at http://www.brookespublishing.com/



Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities, by Beth Marks, Jasmina Sisirak, & Tamar Heller



Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Program, by Beth Marks, Jasmina Sisirak, & Tamar Heller

## **Other Resources**

Kramer, J. (2009). I am not my brother's keeper. In Don Meyer (Ed.) *Thicker than water: Essays by adult siblings of people with disabilities.* The book can be ordered from Woodbine House at <u>http://www.woodbinehouse.com/</u>main.asp Q product id E 978-1-890627-91-1

### Dementia in Older Adults with Intellectual Disabilities, (March, 2009).

A report on the state of the science on dementia in older adults with intellectual disabilities from the International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Research Group on Aging. Download at no cost from <u>www.iassid.org</u>

# **Other Resources**

Participation of Individuals with Developmental Disabilities and Families on Advisory Boards and Committees (2009). Caldwell, J., Hauss, S., Stark, B., Journal of Disability Policy Studies, 20(2), 101-109.

**Preventive Health Care Screening Guidelines for People Aging with Intellectual and Other Developmental Disabilities**, (2009). New York State Office of mental Retardation and Developmental Disabilities.

Can download at no cost from the website: http://www.omr.state.ny.us/document/image/hp brochures preventhealthfinal.pdf

Thinking Ahead: My Way, My Choice, My Life at the End. (2009). A workbook and DVD for people with DD. California Department of Developmental Services. This is a consumer friendly workbook to assist people in making decisions about the end of their life. This workbook and DVD were funded by a 2006-07 DDS Wellness grant. Can download workbook at no cost at <u>www.dds.ca.gov/ConsumerCorner/Publications.cfm</u>

**People Planning Ahead: A Guide to Communicating Health Care and End of life Wishes (2009). by Leigh Ann Kingsbury, AAIDD, Cost: \$19.95** *People Planning Ahead* provides a comprehensive and structured way to ensure that loved ones receive care respecting their wishes and conforming to their personal, cultural, and religious beliefs during times of chronic and terminal illness, or severe disability. Accompanying CD-ROM contains electronic forms from Manual.

American Bar Association Commission on Law and Aging has three good resources on health care advance planning that can be downloaded at no charge from its website <u>www.abanet.org/aging/publications/</u><u>onlinepublicationsconsumers.shtml</u>

Consumer's Tool Kit for Health Care Advance Planning Making Medical Decisions for Someone Else: A How-To Guide Myths and Fact About Health Care Advance Directives

End of Life: Helping with Comfort and Care (2008). Bethesda, MD: National Institute on Aging

This book provides an overview of issues commonly facing people caring for someone nearing the end of life and contains suggestions from practitioners with expertise in helping individuals and families through this difficult time. It can help readers work with health care providers to complement their medical and caregiving efforts. Download at no cost from <u>http://www.nia.nih.gov/HealthInformation/Publications/endoflife/</u> Paper copies also can be ordered at no cost.

Caring Connections <u>http://www.caringinfo.org/</u> a program of the <u>National Hospice and Palliative Care Organization</u> (<u>NHPCO</u>), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.



### **Open the Door, Get 'Em a Locker: Educating Nursing Students with Disabilities**

This documentary film produced by Bronwynne Evans, RN, PhD and Beth Marks, RN, PhD chronicles the experience of a nursing student who entered a baccalaureate program using a wheelchair. The 23 minute film provides a forum for the voices of nursing students, faculty, administrators, and agency nursing staff to discuss trials and triumphs encountered during this experience.

It is a real life example of the exploration of roles and responsibilities in nursing education, experiential learning, shifting perspectives, and being a part of old ways turning into new ways in the world of nursing.

See film trailer at http://www.nurseswithdisabilities.org/

## **Upcoming Events**

### CONFERENCES

### October 16-19,2009

### The CP Group Conference VI: Life and Times with Cerebral Palsy, Arlington, VA

### http://www.thecpgroup.org/

The CP Group is a national organization of adults with cerebral palsy. The conference is an opportunity to address CP-related problems, to socialize and to network.

### October 18-19, 2009

## The Pathways to Future Destinations: Experiences in Grief, Aging and Life Conference, Boling Center for Developmental Disabilities, Memphis, TN

### http://destinationsconference.eventbrite.com/

The Pathways to Future Destinations conference will highlight the needs of persons with disabilities and their families as they plan for the future.

### October 21-23

Rosalynn Carter Institute for Caregiving National Summit and Training Institute, Americus, GA The purpose of the summit, themed "Crossing the Bridge from Science to Service," is to provide professionals in the caregiving field with strategies for effective implementation of evidence-based programs in community settings. For more information, visit: <u>http://www.rcisummit09.org/</u>

### November 2-5, 2009

### Building a Community-Connected and Community-Connecting Organization, Baltimore, MD

### http://www.nlcdd.org/mini-institutes.html

The National Leadership Consortium on Developmental Disabilities and The Council on Quality and Leadership present this mini-institute. Participants will leave this session with practical take-home plans for achieving significant shifts in organizational direction and with a clear understanding of what being a communityconnected and connecting organization means to the organization, staff, and the people you support.

### November 5, 2009

### 9th Annual Coleman Institute Conference: Cognitive Disability and Technology in an Age of Uncertainty, Westminster, CO <u>http://www.colemaninstitute.org/Conferences/Coleman2009/Coleman2009.php</u>

This free conference highlights the following distinguished speakers: James K. Galbraith, Tamar Heller, Jay Lundell, Ann Turnbull, and Rud Turnbull. Topics include smart solutions in recreation, best practices in using technology to improve quality of life, contemporary issues in cognitive disabilities and technology, new approaches to aging and cognitive disabilities, and progress in smart home technologies.

## **Upcoming Events**

### November 7-11, 2009

American Public Health Association 137th Annual Meeting & Exposition, Philadelphia <u>http://</u>www.apha.org/meetings/

### November 8-11, 2009

Association of University Centers on Disability Annual Meeting and Conference: Challenges and Opportunities for Change, Washington, DC <u>http://www.aucd.org/template/page.cfm?id=641</u>

The 2009 AUCD Conference is centered around the network members and the disability community gathering together to address the opportunities and challenges presented by current changes in the economic, political, social, and environmental climate.

### November 18-21, 2009

TASH 2009 Conference: If Not Us, Who? If Not Now! When?, Pittsburgh <u>http://www.tash.org/2009tash/</u> Scholarship and volunteer opportunities are available to assist with conference expenses.

### November 18-22, 2009

Gerontological Society of America 62<sup>nd</sup> Annual Meeting, "Creative Approaches to Healthy Aging," Atlanta, GA <u>www.geron.org</u>

### **DD Formal Interest Group Research Symposium**

Friday, November 20, 8am-9.30am at Atlanta Marriot Marquis, Marquis Level, Room M102

"Approaches for Health Parity and Assessment for Older People with Intellectual Disabilities". E. Perkins (Chair); E. Ansello (Discussant).

- Health Status and Health Care Access among Adults with Intellectual and Developmental Disabilities Living at Home <u>K. Hsieh</u>; K. Yamaki
- Ascertaining Health-Related Information on Adults with Intellectual and Developmental Disabili ties: Data Collection and Results Using the Rochester Health Status Survey <u>L. M. Robinson</u>; P. W. Davidson; C. M. Henderson; M. P. Janicki
- Adverse Drug Reactions and Adults with Down syndrome <u>R. Lucchino</u>

### **DD** Formal Interest Group Business Meeting

Friday, November 20, 6.30pm-8pm at the Hilton in Room 202.

### November 20-21, 2009 Autism Spectrum Disorders: From Childhood through Adulthood, Cambridge, MA <u>http://</u> www.challiance.org/academics/cme\_documents\_07-08/09\_AutismDisorder.pdf

### WEBINARS

### October 13 & 27; November 10

### How to Use the Medicaid Reference Desk to Learn About Medicaid Services for People with Disabilities

The Medicaid Reference Desk is committed to offering accessible, comprehensive, understandable information about Medicaid services for people with disabilities. We are conducting a free webinar to show people how to find the information they need on our website. Go to

http://www.aucd.org/template/event.cfm?event\_id=1971&id=290&parent=290 to select a time and date. Register at www.thedesk.info/teleconf/

### Aging and End of Life Webinar Series

AAIDD, AUCD, The Arc , ANCOR, & UIC RRTC on Aging & DD at UIC are cosponsoring a webinar series on aging and end of life care issues that service systems and providers need to consider now that adults with I/DD are living longer and are increasingly likely to outlive their parents. Webinars are scheduled for the 3<sup>rd</sup> Wednesday of each month through February at 1 -2 PM Eastern time. Go to <u>www.aaidd.org</u> for presentation descriptions and register at <u>https://www1.gotomeeting.com/register/157268416</u>

### October 21:

*COMPETENCE AND COMPASSION – Critical Qualities in Effective Supports for Individuals with Dementia* **Speaker:** Genny Pugh, MS, LPA, FAAIDD, Executive Director, Turning Point Services, Inc.

### November 18:

### Aging and End of Life: Crisis or Opportunity?

**Speaker:** Bill Gaventa, M.Div., Associate Professor, Pediatrics, Community & Congregational Supports, The Elizabeth M. Boggs Center on Developmental Disabilities, Robert Wood Johnson Medical School/UMDNJ

### December 16:

### End of Life Through a Cultural Lens

Speaker: Tawara Goode, PhD, Associate Director Georgetown UCEDD, Georgetown University Center for Child and Human Development

### January 20:

Topic: Pending Speaker: To Be Determined

### February 17:

### Principles of Medical Ethics in Health Care Provisions

Speaker: Michael Henderson, M.D., University of Rochester, Strong Medical Center.