

# Brief Report

## State of the Science Symposium on Aging and Developmental Disabilities<sup>1</sup>

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*Abstract* The overall goal of the 2007 *State of the Science Symposium on Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Community Living* (held in Atlanta, Georgia, U.S.A.) was to increase the understanding and definition of how to improve the health, psychosocial well-being, and community participation of older adults with intellectual and developmental disabilities. The symposium consisted of four main tracks (neurodevelopmental conditions; health care services, health promotion needs, and health literacy; family support and intergenerational caregiving; and environmental barriers and supports to community living). The symposium's participants recommended a greater focus on a research agenda that would serve to increase the knowledge on the lifespan trajectory for individuals with intellectual and developmental disabilities and on identifying methods for developing and assessing effectiveness of practices and policies for individuals with developmental disabilities, their families, and their service providers.

*Keywords:* aging, environmental influences, families, health, intellectual disabilities, neurodevelopmental conditions

### INTRODUCTION

A symposium on *State of the Science in Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Community Living* was held on May 21–22, 2007, in Atlanta, Georgia, U.S.A. Sponsored by the University of Illinois at Chicago's Rehabilitation Research and Training Center on Aging with Developmental Disabilities, it was framed to examine current knowledge and to set the agenda for

further research on the unique life course of adults with intellectual and developmental disabilities (I/DD) and to define the supports needed for promoting their health and community participation. The symposium consisted of four main tracks: neurodevelopmental conditions; health care services, health promotion needs, and health literacy; family support and intergenerational caregiving; and environmental barriers and supports to community living.

The symposium's specific objectives consisted of the following:

- Improve the knowledge of the biologic and psychosocial aging of adults with genetic and nonspecific neurodevelopmental conditions.
- Understand health care services for adults aging with I/DD, including ways to promote better health care, health literacy, health promotions, and end of life care.
- Better understand the needs of families of adults with I/DD to promote family support policies that improve their well-being.
- Develop strategies to promote community participation through environmental and technological interventions.

The first track, the Atlanta Charrette Study Group on Neurodevelopmental Conditions and Aging, was cosponsored by the Developmental Disabilities Branch of the United States Centers for Disease Control and Prevention (Janicki, Henderson, & Rubin, 2008). The Charrette's participants examined the extant

Received May 17, 2008; accepted August 22, 2008

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<sup>1</sup>The 2007 *State of the Science Symposium on Aging with Developmental Disabilities: Charting Lifespan Trajectories and Supportive Environments for Healthy Community Living* was sponsored by the Rehabilitation Research and Training Center on Aging and Developmental Disabilities, in collaboration with the American Association on Intellectual and Developmental Disabilities (AAIDD). Key funding organizations included the National Institute on Disability and Rehabilitation Research (NIDRR) (Grant #H133B031134); Agency for Healthcare Research and Quality (AHRQ) (Grant #1 R13 HS016992-01); Centers for Disease Control and Prevention; Coleman Institute for Cognitive Disabilities, University of Colorado System; College of Applied Health Sciences, University of Illinois at Chicago (UIC); and Easter Seals. Other sponsors included the Association of University Centers on Disabilities, American Association on Intellectual and Developmental Disabilities, International Association for the Scientific Study of Intellectual Disabilities, and the Institute on Human Development at the University of Georgia.

knowledge on the long-range effects and interactions with aging of a number of neurodevelopmental conditions, including autism, cerebral palsy, Down syndrome, fragile X syndrome, Prader-Willi syndrome, spina bifida, and William's syndrome. It was observed that with the exception of Down syndrome and cerebral palsy, significant information on the lifespan changes and aging effects is missing on most of these conditions. The Charrette's main conclusion was that additional research and clinical investigatory work is needed to better understand the long-term effects of aging on persons with these conditions. Primary recommendations included new work toward the identification and description of the presentations and courses of age-related medical disorders that are common among these conditions; determination of the comparative prevalence and incidence of specific medical conditions between persons with neurodevelopmental disabilities and the general population; use of the prevalence and incidence data to better understand risk factors for these concomitant diseases; promotion of surveillance, screening, and specific treatment protocols for health; and the institution of a program of translational research that prioritizes older-age-related conditions.

The second track's work group addressed Health Services, Health Promotion, and Health Literacy (Marks, Sisirak, & Hsieh, 2008). Participants identified unmet needs related to health and health care and determined training, research, and policy needs addressing the demands for increasing health-care services and resources, end-of-life and palliative care, and health literacy. Key issues addressed included: (1) major health-related disparities for adults with I/DD; (2) the impact of internal and external factors on health-care services and resources, end-of-life and palliative care, and health literacy for adults with I/DD; and (3) frameworks that can be used for understanding and promoting health-care services and resources, end-of-life and palliative care, and health literacy. This group's participants identified a number of research and practice needs related to primary care, health promotion, disease prevention, illness care, end-of-life issues, and palliative care. The Work Group noted that health-care services for adults with I/DD may occur in a variety of settings including community-based programs, private practices, and community-based agencies supporting persons with disabilities. Major gaps identified were related to health disparities because of underdiagnosis, misdiagnosis, less chance of receiving prompt treatment, limited access to providers, lack of research information, transportation barriers, and lack of accessible medical equipment. Models of care including variables related to translation, sustainability, accessibility (e.g., affordability, availability), acceptability (e.g., cultural relevancy, satisfaction), and equity need to be developed.

The third track, served by the Family Support and Intergenerational Caregiving Work Group, was designed to discuss the impact of family issues (Heller & Factor, 2008). This track's participants constructed a research and policy agenda that would be expected to result in a better social, health, and economic well-being for adults with I/DD and family carers. Key issues addressed were: (1) demographic challenges; (2) long-term outcomes, poverty, and cultural minority status; (3) interdependent roles of family members; and (4) family support policies and practices. The Work Group identified the following major gaps in knowledge that need to be included in a future research agenda: data on the demography of families (including information on cultural

minorities and families living in poverty); research on the interdependent roles of various family members in providing support to each other (including siblings, grandparents, and the person with disabilities); and development and assessment of models for providing supports to families and that bridge the aging and disability networks.

The fourth track's work group addressed Environmental Barriers and Supports to Health and Participation (Hammel, Jones, Smith, Bodine, & Johnson, 2008). The participants worked to provide a research and policy agenda targeting the assessment and evaluation of environmental factors influencing the health, function, and participation of people with I/DD. Key issues addressed were: (1) the "built environment" (including homes and communities); (2) assistive and information technology design and use; (3) social environment factors and interventions; and (4) environmental access and participation policies, legislation, and system change implications. The group identified gaps in knowledge and priorities for future research including multivariate analyses of attributes of the "built environment"; large-scale intervention trials of assistive and information technology use with people with cognitive disabilities; development and testing of social, peer mentoring, and self-management interventions as applied to people with I/DD; incorporation of environmental health research methodologies, such as "GIS [Graphic Information System] mapping" and participatory action approaches that actively include people with I/DD in the research process; and analyses of the impact of legislative and policy initiatives related to least restrictive community living and participation for people with I/DD.

Overall, it was anticipated that the symposium's outcomes would serve to increase the scientific knowledge among professionals working in the areas of health and function, as well as family supports, among people with I/DD; arrive at consensus on the research findings to date and their useful applications; and help set a future research agenda on examining health changes, support-driven enablements, and proactive clinical applications across the lifespan for persons with intellectual and related developmental disabilities. Most importantly, the discussions showed that the field is now transcending the usual notions of aging among people in general and looking at several fundamental outcomes: improving longevity and improving quality of life—via efforts to better understand the aging process, how life events affect and interact with aging, and how the promotion of a longevity and healthy aging agenda can be more functional. General recommendations focused on: (1) advancing the knowledge and improvement in the delivery of quality health care to adults with I/DD (including specific neurodevelopmental conditions); (2) eliminating the disparity in health services between adults with I/DD and the general population; (3) developing progressive policies and interventions that support the health of older family carers (including minority and low-income families); (d) promoting the physical and emotional health outcomes of adults with I/DD by examining their critical tie to environmental factors; and (4) developing partnerships with stakeholder organizations and building their capacity to participate in health service research by developing and disseminating diagnostic and treatment guidelines and best practices.

Overall, bringing to fruition the symposium's research agenda would increase our knowledge on the lifespan trajectory for

individuals with I/DD and of methods for developing and assessing effectiveness of practices and policies on individuals with I/DD, their families, and their other service providers.

The full report and recommendations of the symposium are available on the University of Illinois at Chicago Web site at [http://www.uic.edu/orgs/rrtcamr/SOS\\_Summary\\_Report\\_3-8-08.doc](http://www.uic.edu/orgs/rrtcamr/SOS_Summary_Report_3-8-08.doc)

#### REFERENCES

- Hammel, J., Jones, R., Smith, J., Bodine, C., & Johnson, M. (2008). Environmental barriers and supports to the health, function, and participation of people with developmental and intellectual disabilities: Report from the State of the Science Symposium in Aging with Developmental Disabilities. *Health and Disability Journal, 1*, 143–149.
- Heller, T., & Factor, A. (2008). Family support and intergenerational caregiving: Report from the State of the Science Symposium in Aging with Developmental Disabilities. *Health and Disability Journal, 1*, 131–135.
- Janicki, M. P., Henderson, C. M., Rubin, L., & the Atlanta Charrette Study Group. (2008). Neurodevelopmental conditions and aging: Report on the Atlanta Charrette study group on neurodevelopmental conditions and aging. *Health and Disability Journal, 1*, 116–124.
- Marks, B., Sisirak, J., & Hsieh, K. (2008). Health services, health promotion, and health literacy: Report from the State of the Science Symposium in Aging with Developmental Disabilities. *Health and Disability Journal, 1*, 136–142.