

ISSUE BRIEF

Aging and People with IDD

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Individuals with intellectual and developmental disabilities (IDD) are living longer for the same reasons as the general population, but particularly due to advances in medical care. The past four decades of research illustrate some unique differences about the experiences of people with IDD in health, retirement, and end of life; however, greater exploration of the factors associated with their health and the aging process is necessary, along with greater demonstration of best practices and evidence-based interventions.

Research on specific conditions associated with IDD has the potential to aid in the development of new interventions and improve the health status of people with IDD. In addition, research on the unique needs of people with IDD surrounding retirement, bereavement, and end-of-life services will increase our understanding of strategies to facilitate person-centered and effective practices to support people with IDD as they age.

► Introduction

Several working meeting conferences over the past 15 years have convened experts to make recommendations for addressing health needs of aging and older adults with IDD (Evenhuis, Henderson, Beange, Lennox & Chicoine, 2001) and to set a research agenda (Heller, 2008). This brief describes the research goals identified by the invited participants of a strand charged with addressing transitions in aging among people with IDD at the National Goals Conference in Washington, DC on August 6-7, 2015. The goals described here are organized under three areas—health, retirement and end-of-life—and consider both the individuals with IDD who are aging and those who provide them with supports or services. There is an overarching need for person-centered approaches across populations and service delivery systems in healthy aging, retirement, later life, and end-of-life transitions. To assure that their perspectives on desirable supports and outcomes are addressed, people aging with IDD should be included in all relevant health and social science research.

► Need for Research

As people with IDD are living lifespans comparable to their non-disabled peers, research is needed to determine what interventions, practices, and models best promote their healthy aging, and research on specific conditions associated with IDD is needed to better direct health care efforts. In addition, research on retirement, late-life transitions, end-of-life planning, and bereavement supports for people with IDD is necessary to assure the highest levels of quality of life and self-direction as they age.

► Healthy Aging Research Goals

Although a number of studies support interventions to promote health, reduce health risks, and prepare adults to engage in preventive health practices and health promotion behaviors, health disparities among people aging with IDD persist. Their health access is poorer than among non-disabled peers; their health problems go unrecognized and may contribute to earlier mortality. Research related to training and service delivery has moved from one-on-one

intervention strategies toward more systematic models; however, health care workers and family caregivers still lack important evidence-based information concerning health, mental health, and palliative care for people aging with IDD. To improve lifelong health, evidence-based interventions, practices, and models that promote healthy aging and longevity for people with IDD must be identified, disseminated, and implemented system-wide.

IMPACT

Jo Ann is 49 and an only child who lives with her 84-year-old mother Bettye Jo. “When Jo Ann was a very young child, they told us she had a disability,” said Bettye Jo.

Bettye Jo underwent vascular bypass surgery on her legs, 8 or 9 years ago, after which she rehabilitated in a nursing home for several months. During that time, Jo Ann lived in a group home, which, according to Bettye Jo, was a very negative experience. Jo Ann later returned to the same group home while Bettye Jo recovered from a second surgery, and while she had a more positive experience during her second stay, she is very resistant to the notion of living in a group home again, even after her mother is no longer alive.

Jo Ann is now enrolled in the HCBS waiver and a service provider comes to their home 7 days per week to assist her. Bettye Jo is grateful for the services Jo Ann receives. “I wish everyone who needed it could get it,” said Bettye Jo. “I use a wheelchair to get around now and I can no longer drive a car. I rely on Jo Ann’s service provider to get her to the doctor and into the community to do things she enjoys.”

Bettye Jo is worried about the future when she is no longer around to take care of Jo Ann. While she has made arrangements for Jo Ann to remain in the family’s home and have a live-in residential service provider assist with daily living tasks, Bettye Jo worries about the quality of services her daughter will receive. “I asked her if she wanted to live at the group home when I’m gone,” said Bettye Jo. “She said she wants to live at home. So, she’s going to live in this house. This is her home. She will have someone working here the whole time. My greatest worry is about who the people will be. I want to know Jo Ann is surrounded by good people. She is my precious love. She is my only child.”

► Health Interventions Research Goals

Research on specific conditions associated with IDD is essential to drive the development of effective interventions and improve the health status of people with IDD. Research findings on aging with IDD in the US are currently limited to longitudinal studies of aging trajectories across a large sample of adults aging with IDD. While large cohorts are important for establishing generally applicable findings, aging trajectories associated with specific conditions cannot be extrapolated. Greater knowledge about age-related issues specific to particular syndromes, for example, the linkage of Down syndrome and conditions such as dementia, would better guide the specific interventions to promote better health and quality of life in later years.

► Retirement and Late-Life Transitions Research Goals

Research to determine the most effective practices to support the growing numbers of people with IDD who have achieved retirement age, including the meaning and experience of retirement and late-life transitions is essential. Most available research on supporting transitions in late life concerns only those who participated in the traditional workforce. Other older adults with IDD may never have taken part in paid employment but may still transition to new patterns of leisure or other meaningful activities in older age. A wide variation of policies, procedures, and regulations across states shape the types of daytime activities and medical supports for people with IDD. It is critical to identify what leads to successful transitions, such as being able to age in place, and to determine specific training and supports necessary for facilitating meaningful, person-centered transitions.

► Bereavement and End-of-Life Research Goals

Health care workers, families, and people with IDD report a lack of preparation for end-of-life issues. In addition, people who work in hospice and palliative care also report that they feel ill-prepared to deliver their services to people with IDD. People with IDD need education to understand dying, death and end-of-life planning, so that they are better prepared when actually confronted with these issues; and family members, support staff, and health care workers need training to assure that the full range of choices and care options are available in this phase of life.

► Conclusion

Addressing these research priorities will achieve multiple meaningful outcomes for people with IDD, including the

delivery of effective health practices, meaningful engagement in retirement activities, and person-centered end-of-life planning associated with comfort, dignity and respect.

► References

- Evenhuis, H., Henderson, C.M., Beange, H., Lennox, N. & Chicoine, C. (2001). Healthy ageing—Adults with intellectual disabilities: physical health issues. *Journal of Applied Research in Intellectual Disabilities* (3), 175-194.
- Heller, T. (2008). Report of the state of the science in aging with developmental disabilities: Charting lifespan trajectories and supportive environments for healthy community living symposium. *Disability and Health Journal*, 1, 127-130.

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