

FACT SHEET

MCCORMACK GRADUATE SCHOOL OF POLICY AND GLOBAL STUDIES
GERONTOLOGY INSTITUTE

Sibling Caregivers of Aging Adults with Intellectual Disabilities¹

Prepared by: Caitlin E. Coyle, Jan Mutchler, and John Kramer

The increased longevity of persons with Intellectual and Developmental Disabilities (IDD)—coupled with the relatively novel expectation that they will be life-long residents of the community with the support of appropriate services and informal assistance—prompts a rethinking of how support will be provided to this vulnerable population in later life. Current cohorts of adults with IDD are the first to routinely experience the frailty and death of their own parents—their original and often primary supports—raising questions about how their siblings will respond. It has been estimated that 640,000 adults with IDD age 60 and older live in the community (Heller and Factor, 2004). This number is expected to double to over 1.2 million by 2030. Although many adults with IDD can live independently in their own apartments or homes, and many others live in group settings, the majority live with family caregivers (Braddock et al., 2005), many of whom are themselves over age 60 (Fujiura, 1998).

A series of 15 in-depth interviews were conducted with middle-aged and older adults who are caretakers of a sibling with IDD. Major areas of questioning included: the history of sibling dynamics; patterns of service utilization; experiences with the transition to sibling caregiver; the role of aging (both sibling and caregiver); and future planning. Data from these interviews revealed a variety of emerging themes:

- Taking on the caregiving role typically “just happened” without much planning involved. Caregivers often related their new roles as caregivers to their relationships with their disabled siblings as children. Caregivers worry about what will happen if their siblings outlive them, but have no plans in place.
- Caregivers found the transition to serving as caregivers challenging and somewhat isolating. They report implications of the role on their life choices as well as uneven support from others in the sibling group.
- The onset of dementia symptoms is the most problematic aging-related disruption in what has often been a long-standing routine. Seeking supplementary support and services for age-related issues is a challenge.
- Caregivers report some distress and resentment. However, any resentment is directed toward others in the sibship, not the sibling with IDD.

¹ Mutchler, J., Coyle, C., Kramer, J. [Family Ties: Sibling caregivers of aging adults with disabilities](#). Gerontological Society of America Annual Meeting, Boston, MA, November 19. Poster Presentation

Implications with respect to populations aging with disability, and sibling caregiving in later life:

- There is a need for education targeting family caregivers of people with IDD around aging issues, particularly in respect to planning for the future.
- More specialized support is needed for sibling caregivers as they age together with their siblings with IDD.
- Stronger infrastructure is needed among aging and disability specialty services providers, particularly improved communication and coordination of existing evidence-based efforts.