Title: Correlates of Current Caregiving and other Roles for Siblings of Adults with Intellectual and Development Disabilities (IDD)

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Introduction: The population of adults with IDD who are 60 years old or older is expected to increase from 641,860 in 2000 to 1.2 million by 2030 (National Center for Family Support, 2000). Due to the inadequacy of adult-disability services in the United States, family members may need to provide caregiving for their brothers or sisters with IDD (Krauss, Seltzer, & Jacobson, 2005). The increase in life expectancy has led to concerns about who will care for adults with IDD. As siblings are the longest-lasting familial relationship, siblings may assume primary caregiving roles for their brothers and sisters with IDD. Yet most sibling caregiving studies only focus on siblings who anticipate caregiving—not siblings who are caregivers (e.g., Burke et al., 2012). Further, recent research has demonstrated that siblings may not be able to accurately anticipate their caregiving roles (Burke, Fish & Lawton, 2005). This study addressed the following three questions: (1) Which characteristics correlate with sibling caregiving?; and (2) Aside from caregiving, what roles do siblings play for their brothers and sisters with IDD?

Method: Participants included 511 adult siblings of individuals with IDD who responded to a national, web-based survey. The survey was developed based on the literature about adult siblings (e.g., Heller & Arnold, 2010; Burke, Taylor, Urbano, & Hodapp, 2012). Sibling respondents were predominantly female, White, and well-educated. Although the average participant age was in the early-40s, respondent ages ranged from 18 through 86 years. Participants resided across 42 states. Their brothers and sisters with IDD had various types of IDD including: intellectual disability; autism; and Down syndrome. We conducted a multivariate regression to determine the correlates of current sibling caregiving. Potential correlates included: closeness of the sibling relationship, degree of sibling contact, parent caregiving, future planning activities, maladaptive behavior of the individual with IDD, functional abilities of the individual with IDD, advocacy activities of the sibling, sibling gender, and family size. In response to sibling roles, participants responded using a text box. We used constant comparative analysis and emergent coding to analyze their responses.

Results: Overall, 53.4% of adult siblings considered themselves as current caregivers for their brothers or sisters with IDD. The multivariate regression was significant and explained 20.0% of the variance. Siblings were more likely to be current caregivers if: they had close sibling relationships; they had more contact with their brothers/sisters; they had advocated for their brothers/sisters; they engaged in future planning; their parents had poor caregiving abilities; and their brothers/sisters had less functional abilities. Regarding sibling roles, we found four roles (in addition to caregiving): (1) acting as guardians; (2) providing emotional support; (3) being advocates; and (4) just being a “typical” sibling.

Discussion: Taken together, these findings tell about primary sibling caregivers. This study revealed the importance of the involvement in advocacy and future planning. Given the high percentage of siblings who were current caregivers, it seems that siblings are indeed fulfilling caregiving roles; support must be provided to these siblings. These findings also highlight siblings’ other roles instead of being a primary caregiver. Also, this study highlighted other roles that siblings may fulfill.

References/Citations: