Title: Exploring the Nature and Correlates of Caregiving among Parents of Adults with Intellectual and Developmental Disabilities

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Introduction: Given the insufficiency of the adult service delivery system and the increase in the lifespans of adults with IDD, parents often remain caregivers to their offspring with IDD into old age (Fujiura, 2014). Although siblings often report anticipating fulfilling caregiving roles (Burke et al., 2012), it is unclear whether parents want to pass on their roles to their offspring without IDD. Further, we know very little about the nature of caregiving including its intensity. To this end, this study had three research questions with respect to parents of adults with IDD: (1) What is the nature of caregiving?; (2) What are the correlates of the intensity of caregiving?; and (3) What is the plan for future caregiving—specifically, who do parents anticipate will fulfill future caregiving roles?

Method: Data were collected from 388 parents of adults with IDD via a national, web-based survey. On average, they were 55.71 years of age (SD = 9.27); their adult offspring were 26.66 years of age, on average (SD = 7.79, range from 18 to 68). Participants answered the following question about the nature of caregiving: “In the last week, how many hours did you spend caring for your child with a disability?” Response options ranged from “none” to “over 60 hours per week”. In response to the plan for future caregiving, participants were asked “Who will provide caregiving to your child with a disability when you are no longer able to provide care?”. Response options included: my other children; other family member; other, and caregiving is not necessary for my adult child with a disability. Regarding independent variables to identify correlates, we examined: parent caregiving ability; the presence of other children without IDD in the family; functional abilities of the youth with IDD (Lawton et al., 1982); and maladaptive behaviors of the youth with IDD (Bruininks et al., 1986). To answer the first and third research questions, descriptive statistics were conducted. To answer the second research question, a regression was conducted.

Result: Many participants (28.4%) provided over 60 hours per week of caregiving. Further, 14.2% and 11.9% reported providing 31-60 hours per week and 15-30 hours per week, respectively. Also, 17.3% provided 5-14 hours per week; 9.0% provided 3-4 hours per week; 7.0% provided 1-2 hours per week and 12.4% provided no hours of caregiving. The regression analysis was significant (p < .001) with a Cox and Snell R² of .34. All independent variables were significantly related to the nature of caregiving. Specifically, when families had more children without IDD, parents reported significantly less caregiving hours (p = .006). Also, there was a positive correlation between parent caregiving ability and caregiving hours (i.e., parents with excellent caregiving ability were more likely to provide hours of caregiving, p < .001). Further, there were positive correlations between the functional abilities and maladaptive behaviors of individuals with IDD and caregiving hours (i.e., when adult offspring with IDD had less functional abilities and/or had greater maladaptive behaviors, parents provided more caregiving hours, p < .001 and p = .002, respectively).

Regarding the future caregiver role, 38.5% reported that their adult offspring without IDD will fulfill caregiving roles. In addition, 11.8% reported that another family member will fulfill a caregiving role; 7.9% reported that caregiving was not necessary for their offspring with IDD. However, 41.8% completed a fill-in response (i.e., “other”) to this question. Of those participants, the response was either “I don’t know” or “the Adult Service Delivery System”.

Discussion: This study has important implications. First, interventions should be targeted to support caregivers especially given that so many caregivers provided over 60 hours per week of caregiving. Second, interventions may be specifically targeted to assist caregivers of individuals with less functional abilities and/or greater maladaptive behaviors. Third, although the presence of adult children without IDD may decrease the number of caregiving hours, many parents reported not relying on siblings to fulfill future caregiving roles. Alarmingly, many of the participants reported not knowing who will fulfill these roles. Some parents reported relying on the adult service delivery system which is unfortunate because 43 states have waiting lists for adult services.

References/Citations: