Title: Identifying the Correlates and Barriers of Future Planning Among Parents of Adults with Intellectual and Developmental Disabilities

Authors: Meghan M. Burke and Catherine K. Arnold

Introduction: As individuals with intellectual and developmental disabilities (IDD) have longer lives, they are beginning to outlive their parents (Fujiura, 2014). Yet, less than half of parents of adults with IDD report engaging in future planning (Freedman & Krauss, 1997). Without future planning, adults with IDD are more likely to face inappropriate placements and crisis situations (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). The purpose of this study was two-pronged: (1) What are the correlates of future planning among parents of adults with IDD? And (2) What barriers do families report in relation to future planning?

Method: Participants were 317 parents of adults with IDD (mean age of the parents was 52.25, SD = 11.38). Participants responded to a national, web-based survey. Independent variables included: severity of maladaptive behaviors of the adult with IDD (Bruininks et al., 1986), functional abilities of the adult with IDD (Lawton et al., 1982), parent participation in training activities, family size, receipt of formal services for the individual with IDD, parent age, and parent educational background. The dependent variable was Future Planning (Heller & Caldwell); this scale was comprised of 11 items to gauge the degree of long-term planning for individuals with IDD. Univariate analyses were conducted to examine relations between the independent variables and future planning. A correlation matrix with the independent variables and the variable inflation factor revealed no multicollinearity. A linear regression was conducted with all of the independent variables. Regarding barriers, participants were asked whether lack of information, financial, family dynamics, or other barriers prevented future planning from occurring.

Results: The regression was significant explaining 28.1% of the variance (F = 18.66, p < .001). When individuals with IDD had less functional abilities and received more formal services, parents were more likely to engage in future planning (p < .001 and p = .03, respectively). When parents were more highly educated and participated in more activities to become knowledgeable about services, they were more likely to engage in future planning (p’s < .001). Also, when parents were older, they were more likely to engage in future planning (p > .001). Regarding barriers, 27.8% of parents reported financial barriers, 24.7% of parents reported lack of information about future planning, and 2.8% reported that their family refused to engage in future planning as a barrier. Further, 17% of the participants wrote “other barriers” and answered (within a text box) about other barriers they faced. The majority of these responses related to the lack of formal services for adults with IDD.

Discussion: It seems that parents who have and can access information, training, and resources for their offspring with IDD are more likely to conduct future planning. The lack of available services, information, and financial barriers may make it harder for less educated and less savvy families to engage in future planning. Practitioners and policymakers should address this uneven playing field by increasing the accessibility of resources for all families to engage in future planning.

References/Citations: