Title: A Pilot Study Evaluating the Outcomes and Feasibility of a Future Planning Program for Siblings of Individuals with Intellectual and Developmental Disabilities

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Introduction: Given the increased longevity of individuals with intellectual and developmental disabilities (IDD), there is growing attention to the phenomenon of aging in this population and their families. Aging individuals with IDD are often cared for by their family members. Almost 75% of adults with IDD live at home with family caregivers, primarily mothers, and 25% of these caregivers are over 60 years of age. As individuals with IDD are beginning to outlive their parents, siblings are often turned to as the next generation of caregivers for individuals with IDD. To prepare for the transition in caregiving roles from parents to siblings, future planning is critical for families of adults with IDD. Yet, in a review of future planning interventions, none of the interventions included siblings of individuals with IDD. Thus, the purpose of this study was to pilot-test the outcomes and feasibility of a future planning intervention (Sibling Training for Early future Planning; STEP program) for adult siblings of individuals with IDD.

Method: This study involved multiple data sources including qualitative data (e.g., individual interviews) and quantitative data (e.g., surveys). By using multiple data sources, we had greater internal validity to demonstrate the outcomes of the STEP program. Because this was a pilot study, we conducted a single-arm intervention design. Participants included 18 siblings whose ages ranged from 20 to 36 years old ($M = 26.28$, $SD = 4.11$). Almost 89% of participants were female and single. Their brother or sister with IDD ranged in age from 18 to 38 years old ($M = 24$, $SD = 7.21$). Outcome measures were collected at three time points: Time 1 (before the STEP program), Time 2 (at the end of the last session of the STEP program), and Time 3 (four weeks after completion of the STEP program). The following measures were collected: Knowledge about adult services (Taylor et al., 2017); Future planning activities (Heller & Caldwell, 2006); Family Communication (Epstein et al., 1983); Empowerment (Koren et al., 1992); and Disability connectedness (Taylor et al., 2017). In addition, formative, summative evaluations, and individual interviews were conducted.

Results: To determine the outcomes of the STEP program, a Friedman nonparametric test was conducted; Wilcoxon signed ranks tests were used to locate significant differences comparing Time 1, Time 2, and Time 3. In comparison to Time 1, at Time 2 survey and Time 3, participants demonstrated significantly greater: future planning activities, $x^2(2) = 28.73$, $p < .001$, $W = .80$; Family empowerment, $x^2(2) = 13.77$, $p = .001$, $W = .36$; Service System empowerment, $x^2(2) = 15.64$, $p < .001$, $W = .43$; knowledge of adult disability services, $x^2(2) = 27.85$, $p < .001$, $W = .77$; family communication, $x^2(2) = 9.13$, $p = .01$, $W = .25$; and disability connectedness, $x^2(2) = 16.73$, $p < .001$, $W = .47$. Aligned with quantitative findings, individual interviews also documented benefits of the STEP program including: having a guide for family communication, connecting with other siblings, increasing knowledge about adult disability services, and having improved empowerment. With respect to feasibility, the STEP program had a high attendance rate (89%), low attrition rate (10%), and high satisfaction (100% reported being satisfied with the STEP program). Participants suggested that future iterations of the STEP program include more content about adult disability services as well as ongoing supports for participants after completing the STEP program.

Discussion: Although researchers have highlighted the importance of future planning for families of individuals with IDD, most future planning studies have focused on maternal caregivers, excluding siblings. Siblings report struggling to learn about adult services and to participate in future planning (Heller & Arnold, 2010). The findings of this study indicate that a future planning intervention can enhance: sibling participation in future planning, empowerment, family communication, and connectedness. Promising directions for future research include examining program outcomes with a bigger sample and a randomized controlled trial (RCT).
References:


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