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A PILOT STUDY OF A FUTURE PLANNING PROGRAM FOR SIBLINGS OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Abstract

Given the increased longevity of individuals with intellectual and developmental disability (IDD), future planning programs are becoming increasingly common. However, although siblings are likely to fulfill caregiving roles for individuals with IDD, siblings have not been included in future planning interventions. The purpose of this study was to evaluate the outcomes and feasibility of the *Sibling Training for Early future Planning* (STEP) program. Using quantitative and qualitative data, 18 siblings of individuals with IDD participated in the study. After completing the STEP program, participants demonstrated significantly improved: feelings of empowerment, disability connectedness, family communication, and knowledge of adult disability services. The STEP program was also feasible given high attendance, low attrition rates, and high participant satisfaction. Implications for research and practice are discussed.

A Pilot Study of a Future Planning Program for Siblings of Individuals with Intellectual and Developmental Disabilities

Due to improvements in medical technology and social conditions, substantial improvements in the lifespans of individuals with intellectual and developmental disability (IDD) and their families have occurred in recent years. In the 1930s, individuals with IDD had a life expectancy of 18.5 years; however, the life expectancy among individuals with IDD is now closer to that of the general population (Bittles, Petterson, Sullivan, Hussain, & Montgomery, 2002). Given the increased longevity of individuals with IDD, there is growing attention to the phenomenon of aging in this population and their families (Hodapp, Sanderson, Meskis, & Casale, 2017).

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 (Braddock, Hemp, Tanis, Wu, & Haffer, 2017). 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 (Hodapp et al., 2017). Indeed, “caregiver” is the most common role that siblings anticipate when their parents are no longer able to provide care (Hodapp et al., 2017).

To prepare for the transition in caregiving roles from parents to siblings, future planning is critical for adults with IDD. Researchers have identified negative outcomes when future planning is not conducted. For example, without future plans, individuals with IDD may be reside in inappropriate settings (e.g., institutions, state operated developmental centers, large congregate settings) and receive limited supports (Hewitt, Agosta, Heller, Williams, & Reinke, 2013). Further, without future planning, family caregivers may have greater emotional stress and anxiety about the future (Freedman, Krauss, & Seltzer, 1997). Yet, even considering the caregiving roles of siblings of individuals with IDD, in a review of future planning interventions, none of the interventions included siblings of indivdiuals with IDD (Authors, in press). Thus, the purpose of this study was to pilot-test the outcomes and feasibility of a future planning intervention for adult siblings of individuals with IDD.

While future planning programs have been developed across the United States, United Kingdom, and Australia (e.g., Bigby, Ozanne, & Gordon, 2002, Craig & Cartwright, 2015, DaWalt, Greenberg, & Mailick, 2018, Heller & Caldwell, 2006), few studies have reported the efficacy of future planning programs. For example, Heller and Caldwell (2006) tested the ‘Future is Now’ program with 29 families of adults with IDD finding that intervention (versus control) group participants demonstrated significantly increased future planning activities and reduced caregiving burden. Similarly, DaWalt and colleagues (2018) conducted a randomized controlled trial (RCT) with 41 families of adults with autism spectrum disorder (ASD) finding that participants who completed (versus did not complete) the ‘Transitioning Together’ program demonstrated significantly decreased depressive symptoms and increased problem-solving. Unfortunately, siblings were not included in either intervention.

To be effective among siblings of individuals with IDD, future planning interventions need to reflect their support needs. A common support need among siblings of individuals with IDD is needing information and resources to navigate adult disability services (Arnold et al., 2012; Rawson, 2010). Lack of knowledge about adult services is a common barrier for parents of individuals with IDD (Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). Given the limited engagement of siblings in the adult disability service delivery system, siblings (versus parents) may have more difficulties in accessing legal and financial services (Rawson, 2010).

Siblings also require empowerment to act on their newfound knowledge. In prior research about parents of adults with ASD, empowerment was necessary for families to use their knowledge about adult services to access needed supports (Taylor et al., 2017). By having greater knowledge and empowerment, siblings may be more likely to conduct future planning (Heller & Kramer, 2009).

Future planning interventions also need to address family communication and disability connectednesss (i.e., the extent to which individuals feel a sense of belonging to the disability community, including other individuals with disabilities and their families). Regarding the former, future planning requires dialogue among all family members, especially siblings who are likely to be future caregivers (Lee, Burke, & Stelter, 2019). Siblings of individuals with IDD consistently report wanting to be involved in future planning discussions (Coyle et al., 2014; Heller & Kramer, 2009). Without future plans, siblings often feel anxious about the future and their own aging (Coyle et al., 2014). However, siblings also report that their parents refuse to communicate about future planning (Coyle et al., 2014). Parents may not want to “burden” their children without IDD with the caregiving responsibilities. For parent-targeted future planning interventions, a peer support model is often used to address future planning (e.g., Heller & Caldwell, 2006). By including peer support in an intervention, there may be an increased connectedness among families as their share a common bond: a child with a disability (Singer et al., 1999). In one of the few interventions for adult siblings of individulas with IDD, Burke and colleagues (2019) conducted a leadership program using a peer support model; after attending the program, siblings reported greater disability connectedness to other siblings of individuals with IDD. Altogether, it is important to determine whether a future planning intervention increases not only family communication but also disability connectedness.

In addition, future planning interventions need to be feasible. Feasibility is often measured by program evaluation (Goddard & Harding 2003). Unfortunately, there is limited extant research about the feasibility of interventions for siblings of individuals with IDD (Hodapp et al., 2017). The absence of such research is problematic because siblings want future planning interventions (Lee et al., 2019). Given that adult siblings of individuals with IDD are likely to be fulfilling multiple caregiving roles (e.g., caring for their own children, their brothers/sisters with IDD and their aging parents, Hodapp et al., 2017), it may be difficult to design and execute a feasible (e.g., well-attended) intervention for siblings. By evaluating the attendance and participant satisfaction of an intervention for siblings, we can gauge whether the intervention may be feasible in this population.

Although researchers have highlighted the importance of future planning for families of individuals with IDD (DaWalt et al., 2018; Heller & Caldwell, 2006), most future planning studies have focused on maternal caregivers, excluding siblings (Heller & Kramer, 2009; Hodapp et al., 2017). Considering their unique roles, siblings should be included in research about future planning. To this end, we developed and tested the *Sibling Training for Early future Planning* (STEP). Specifically, this study had two research questions:

1. Among adult siblings of individuals with IDD, after completing the STEP program, are there changes with respect to: knowledge about adult service, future planning activities, family communication, empowerment, and disability connectedness?
2. Among adult siblings of individuals with IDD, what is the feasibility of STEP program with respect to attendance, attrition, and participant satisfaction?

We hypothesized that siblings who completed the STEP program would have greater: knowledge about adult services, family communication, empowerment, disability connectedness, and completion of future planning activities. Also, we hypothesized that the STEP program would be feasible based on high attendance and low attrition as well as high participant satisfaction.

Method

Design

This study involved multiple datasources including qualitative data (e.g., individual interviews) and quantitative data (e.g., surveys). By using multiple datasources, 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 (i.e., we used an intervention group without a control group).

Participants

In total, 18 siblings participated in this study. To be included in the study, individuals needed to: be over the age of 18 and have a transition-aged sibling (i.e., over the age of 14) with IDD; participate in the STEP program; and complete the research procedures. We excluded siblings who had been involved in previous future planning programs, as such programs may have influenced their future planning. We also excluded current caregivers for their brothers or sisters with IDD because current sibling caregivers have already transitioned into caregiving roles, and thus, future planning may look different for these individuals (i.e., they may be planning for their own mortality versus their parents).

As shown in Figure 1, 27 siblings initially expressed interest in the study. All 27 siblings participated in the screening; seven siblings did not meet the inclusionary criteria as they could not attend the specific dates of STEP program. Twenty siblings met all of the study requirements and provided written consent prior to participation. However, two siblings withdrew from the study as they missed more than two sessions of STEP due to changes in their work schedules. Overall, 18 siblings were assigned to three cohorts based on their schedules. Each cohort had five to eight participants. We conducted an ANOVA to identify demographic differences among three cohorts. We found no differences with respect to: age of the sibling, age of the brother/sister with IDD, ethnicity, educational level, income, and marital status. Of the 18 siblings of individuals with IDD who completed all study requirements and completed the STEP program, 16 siblings were female. Participant ages ranged from 20 years to 36 years (*M* = 26.28, *SD* = 4.11). Further, their brothers and sisters with IDD ranged in age from 18 to 38 years old (*M* = 24, *SD* = 7.21). See Table 1 for detailed information.

Recruitment. We recruited participants through local and statewide agencies and community organizations (e.g., support groups, disability agencies) and the Sibling Leadership Network. We conducted targeted recruitment to retain culturally and racially diverse siblings. To this end, we worked with community-based agencies to recruit diverse participants (Magaña, 2000). Recruitment flyers were disseminated via electronic and hard copy formats. Further, a selective snowball sampling technique was used. Thus, interested participants could refer their friends and colleagues who were siblings of individuals with IDD to the STEP program. Each participant received a $100 gift card for participating in the study.

Setting. The STEP program was delivered in-person in Illinois with simultaneous video conferencing to participants in other states. As a result, participants were from Illinois, Wisconsin, Pennsylvania, and New York. The STEP program was delivered in-person either at a library or University setting.

Procedures

The study was approved by University Institutional Review Board. After receiving written informed consent, data were collected from participants at three time points: Time 1 (before the STEP program: pre-intervention), Time 2 (at the end of the last session of the STEP program: post-intervention), and Time 3 (four weeks after completion of the STEP program: follow-up). The survey was identical across the time points. In addition, we collected formative and summative evaluations. Specifically, at the end of each session, participants completed formative evlauations. Summative evaluations were completed at the conclusion of the last session of the STEP program.

Lastly, two researchers conducted individual interviews with participants one week after completing the STEP program. To ensure fidelity to the interview protocol, the first author trained two graduate assistants in interview methods before conducting the interviews. Then, the researchers scheduled an interview with each participant at the time and date preferred by the participant. Participants could choose to conduct the interview either over the phone or in-person; all participants chose the phone. The researchers took detailed field notes throughout each interview to note the key elements of participants' responses. In the last five minutes of each interview, the researchers summarized the main responses of the interview asking for feedback and clarification from the participant. Each interview lasted between 20 and 40 min. Also, each interview was audio-recorded and transcribed verbatim.

STEP program. In developing the STEP program, we adopted two theoretical frameworks (i.e., bioecological theory and adult learning theory) to inform the scope, sequence, and rationale for the intervention. Specifically, the STEP program reflected the four environmental systems in bioecological theory (Bronfenbrenner, 1979) by addressing: (a) communication among families of individuals with IDD (i.e., the microsystem); (b) sibling peer support and available programs for siblings of individuals with IDD (i.e., the mesosystem); (c) empowerment to navigate adult disability services (i.e., the exosystem); and (d) knowledge to access services for individuals with IDD (i.e., macrosystem).

The STEP program was developed based on other sibling trainings (i.e., *Journey Forward*, WisconSibs, 2019) and future planning traings (i.e., *Future is Now*, Heller & Caldwell, 2006). The STEP program included four, 2-hr sessions. In addition, participants were asked to complete a letter of intent (LOI) outside of the sessions. The LOI is a form to facilitate and document current and future plans for an individual with IDD. After each session, the facilitator encouraged participants to complete specific sections of the LOI. For example, after the second session, participants were asked to complete the LOI with respect to planning for their brothers and sisters with IDD. It takes at least 2 hrs to complete the entire LOI. See Table 2 for an overview of the goals for each session.

Treatment fidelity. To assess treatment fidelity, we used two methods: intervention checklists and reliability checks (Gersten, Fuchs, Compton, Coyne, Greenwood, & Innocenti, 2005). The first author facilitated all of the STEP sessions; the third and fourth authors watched a video of each session and assessed whether the goals were met. Each session met 85-100% of the goals; the average number of goals met was 96.25%.

Measures

Knowledge about adult services. Adapted from an existing knowledge measure (Taylor et al., 2017), the knowledge measure included 10 multiple-choice questions about adult services (e.g., guardianship, Medicaid). For example, a question was: “Which of the following is NOT a requirement for Supplemental Secruity Income?”. Each question was followed by choices, one of which was correct. Each response was coded as either (0) *incorrect* or (1) *correct*, with potential scores ranging from 0 to 10 and higher scores indicating greater knowledge of adult disability services.

Future planning. This scale consisted of 11 questions about future planning (Heller & Kramer, 2009). An item was: “Have you and your family discussed future plans with your brother or sister with a disability?”. Responses were dichotomous: (0) *no* or (1) *yes*. A summed variable ranging from 0 to 11 was used for this study; this scale had strong internal consistency reliability (Kuder-Richardson coefficient = .86; Burke & Heller, 2016). Kuder-Richardson coefficient for Time 1, Time 2, and Time 3 were .60 for this study.

Family communication. We included two subscales of the McMaster Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983): the Problem-solving subscale and Communication subscale. Response ranged from (1) *strongly disagree* to (4) *strongly agree*. Higher scores indicated positive family functioning. Previous studies indicated high reliability for both subscales (e.g., for the Problem-solving subscale, Cronbach’s alpha = .79; for the Communication subscale, Cronbach’s alpha = .78; Degeneffe, 2017). The current study reported high reliability (e.g., for the Problem-solving subscale, Cronbach’s alpha ranged from .72 to .86, for the Communication subscale, Cronbach’s alpha ranged from .64 to .65).

Family empowerment. The Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) was designed to measure empowerment among families of individuals with disabilities. For this study, the Family subscale and Service System subscales were used. Each item had a 5-point Likert scale ranging from (0) *not true at all* to (4) *very true*. Previous studies indicated high internal consistency reliability (e.g., for the Family subscale, Cronbach’s alpha = .70; for the Service System subscale, Cronbach’s alpha = .90; Caldwell, Jones, Gallus, & Henry, 2018). The current study also indicated high reliability (e.g., for the Family subscale, Cronbach's alpha ranged from .87 to .90; for the Service System subscale, Cronbach's alpha ranged from .86 to .90).

Disability connectedness. Disability connectedness among siblings was assessed by adapting a seven-item disability connectedness measure (Taylor et al., 2017). For example, an item was: "To what extent do you feel that you are an 'insider' in the sibling disability community in your local area?". Response options ranged from (1) *not at all* to (5) *very much so*. A previous study indicated high internal consistency reliability of this scale (Cronbach's alpha = .89; Burke et al., 2019). The reliability was also high for the current study (Cronbach's alpha ranged from .85 to .91).

Formative evaluation. Participants completed a five-item, close-ended formative evaluation at the end of each STEP session. For example, participants were asked: "How did you feel about this session?"; and "What do you think about instructor delivery, course content, and course materials?". Participants were also asked "How satisfied were you with this session?" with response options ranging from 1 (*not at all satisfied*) or 4 (*very satisfied*).

Summative evaluation. Following completion of the four STEP sessions, participants completed a 30-item summative evaluation. The measure included open and close-ended questions with respect to satisfaction with the: speaker, content, logistics, and overall perceptions of the program. Example items included: "What did you think about the length of each session?" "Are there any other topics you think the training should include?"; "What kind of ongoing support would better enable you to conduct future planning for individuals with disabilities?"; and "Please indicate your degree of satisfaction with the training". With respect to the latter, response options ranged from 1 (*not at all satisfied*) or 4 (*very satisfied*).

Interview Protocol. A semi-structured interview protocol was developed based on extant literature about future planning (e.g., Heller & Caldwell, 2010). To ensure content validity, three researchers in the disability field reviewed the questions. A total of 10 questions were included in the protocol. Questions included: “Did you notice any changes in your family since the project began? If so, what changes did you notice?”

Data Analysis

The Statistical Package for Social Sciences (SPSS) for Windows, version 24.0 was used to conduct all analyses. To determine the outcomes of the STEP program, we conducted a Friedman nonparametric test. Then, Wilcoxon signed ranks tests were used to locate significant differences comparing Time 1, Time 2, and Time 3 data. Given the small sample size (N = 18), normal distribution of the data could not be assured (Hill & Lewicki, 2007). Thus, we proceeded with non-parametric statistics which are more appropriate for small sample sizes (Sheskin, 2004). Specifically, time was entered as the independent variable. With respect to effect size, we calculated Kendall’s W (Coefficient of concordance), which uses Cohen’s *d* guidelines to determine the magnitude of effects (i.e., 0.1 (small effect), 0.3 (moderate effect) and above 0.5 (strong effect) (Hill & Lewicki, 2007).

For feasibility, we conducted descriptive statistics for the quantitative data and emergent coding (Patton, 2002) for the open-ended questions to assess the formative and summative responses and interview data. Regarding the latter, following each interview, the research assistants transcribed the interviews verbatim and all names were replaced with pseudonyms to protect participant anonymity. We (i.e., the first author and one of the research assistants) used constant comparative analysis (Glaser & Strauss, 1967) and emergent coding (Patton, 2002) to analyze the data. Specifically, we independently coded the transcripts using a line-by-line approach. We constantly compared new data to previously coded data to see if the new data represented a new idea or belonged to an existing code (Creswell, 2003). In total, we found 38 codes. Then we grouped the codes into categories and organized the categories into four themes. To ensure trustworthiness, we member-checked the themes with all participants; no changes were made. We also conducted peer-debriefing between researchers, and datasource triangulation (e.g., comparison of the transcripts to the survey and evaluation data).

Results

Outcomes of the STEP program

As shown in Table 3, a Friedman test indicated significant differences among Time 1, Time 2, and Time 3 surveys in relation to: future planning activities, knowledge of adult disability services, empowerment, family communication, and disability connectedness. Specifically, in comparison to Time 1, at Time 2 and Time 3, participants demonstrated significantly greater: future planning activities, $x^2(2) = 28.73$, $p < 0.001$, $W = .80$; Family empowerment, x^2 $(2) = 13.77$, $p = .001$, $W = .36$; Service System empowerment, x^2 $(2) = 15.64$, $p < 0.001$, $W = .43$; knowledge of adult disability services, $x^2(2) = 27.85$, $p < 0.001$, $W = .77$; family communication, x^2 $(2) = 9.13$, $p = .01$, $W = .25$; and disability connectedness, $x^2(2) = 16.73$, $p < 0.001$, $W = .47$.

Aligned with quantitative findings, individual interviews also documented changes after the STEP program. Specifically, participants reported the following benefits: having a guide for family communication, connecting with other siblings, increasing knowledge about adult disability services, and having improved empowerment.

Guide for family communication. Participants reported greater family communication after completing the STEP program. Specifically, participants initiated family conversations about future planning using the LOI as a guide. Participants reported various reactions from their families when they initiated such discussions. Reactions included: delight, open, resistant, and shock. Although family members had different reactions, using the STEP training and/or the LOI enabled siblings to initiate future planning conversations. The 24-year-old sibling of a sister with Down syndrome reported,

> I think that having a written template for the letter of intent with the list of questions were helpful because when talking to my parents, I can set the list down in front of us. All the questions are there so that I won't avoid asking questions that feel harder—that I feel uncertain about.

Disability connectedness. Most participants valued the experience of sharing their own stories and hearing other sibling stories. Notably, all participants reported that the STEP program was the first time they had received support from other siblings. A 33-year-old brother of an individual with Down syndrome shared, "I was hoping to connect to other siblings to hear about their experiences also. This is really one of first times I've gotten to do that." After the program, participants reported engaging in other disasbility activities. For example, some siblings: joined a sibling advocacy group (i.e., SibNet, Sib20), became board members for the Sibling Leadership Network, and befriended other siblings of individuals with IDD.

Empowerment. Participants reported greater empowerment in advocating for: their brother or sister with IDD; other families of individuals with IDD; and future planning. For example, a 26-year-old sister of an individual with multiple disabilities reported, "I think it's nice to have a group of people say, 'Yes, your role as a sibling is validated, and you should be part of this conversation.'" Notably, participants also reported empowering the self-determination of their brothers/sisters with IDD. A 26-year-old sister of an individual with ID reported,

> I think it was really nice to have him be central to it rather than my parents. Every time we talk about the future beforehand they'd tell me like, “Oh, well we have this set up. We have this set up.” But my brother wasn't really central to that. So, it definitely impacted our family because now we have this letter [of intent].

Further, a participant who was a special education teacher reported empowering other families to conduct future planning. She reported, “I help them [families of my students with disabilities] advocate for their son or daughter's future. So along the way, I think this just benefits personally my job, and I think in the community as well.”

Knowledge about the adult service disability systems. After completing the STEP program, participants reported a more comprehensive understanding of adult disability services with respect to: legal and financial information; relevant professionals (e.g., special needs trust attorneys); and adult disability services in various states. Further, participants reported being able to share their newfound knowledge within their own families and with other families . For example, a 26-year-old sister of a 20-year-old sister with ID reported,

> The speech pathologist at my school….she actually has a brother with Down syndrome as well. So, her mother had just recently asked her if she would become the primary caregiver, and she was a little shocked. Then, I shared with her that I was doing this [STEP] program and I told her I would share my binder with her so she can get the resources. So, I just thought it was really interesting that I was able to share this knowledge as well with people who are actually going to start going through it.

Because participants were from a variety of locations, they were able to discuss services in different states. Specifically, a 26-year-old sister of an individual with ID reported:

> I discussed it [service systems in other states] with people in my [STEP] group. Their families are in different states across the country so I think that I became aware that each state has different rules and eligibility criteria which is something I had never thought about because I always have focused on Illinois.

Feasibility of the STEP program

We evaluated the feasibility of the intervention based on attendance, attrition rate, and participant satisfaction.

Attandance and attrition. With respect to attention and attrition, 77.78% (*n* = 14) of the STEP participants attended all four sessions. Notably, 22.22% (*n* = 4) of the STEP participants missed one session; however, each of these participants reported that they viewed the recording of the missed session. The attrition rate was 10% (*n* = 2). Two participants only attended the first STEP session. They withdrew from the study due to a conflict with their schedules and the dates/times of the STEP sessions.

Participant satisfaction. In the summative evaluation, when asked to indicate their degree of overall satisfaction with the STEP program, 83.3% (*n* = 15) of the participants reported that they were “highly satisfied,” and 16.7% (*n* = 3) of the participants indicated that they were “satisfied.” Upon compiling all of the formative evaluations, 100% of siblings reported that the instructor delivery, course content, and course material were “good” or “excellent”. Notably, when asked about the length of each STEP session, almost 30% of siblings reported that the third session (i.e., legal and financial planning, adult disability services) was “too short.” Except for third session, all sibling rated “Just right” with respect to the length of the other sessions. In the individual interviews, half of the participants reported that the length of the entire STEP program should be longer. A 24-year-old sister reported,

> I think the only thing was that it seemed really short. More time to dive into more of the topics we discussed or we could have a sibling panel that lasted all two hours. Something like that would probably helpful but in terms of topics covered, I can't think of anything I wanted to know and didn't know about.

Recommendations for future STEP trainings. When asked if there were other topics the STEP program should have covered, based upon the summative evaluations and individual interviews, only two participants offered suggestions: fostering self-advocacy in your brother/sister with IDD and discussing housing options. For example, a sister who is a researcher in disability field reported that, “But I do think just talking about supported decision making and alternatives to guardianship and why . . . would've been really interesting.” In addition, a 29-year-old sister reported,

> There could have been more time dedicated to talk and discussing all of the different housing options. There are so many different types of housing. I think if we'd had more time to expand on that topic, and the pros and cons of all of them, that would have been helpful.

The rest of the participants reported that the STEP program should not be changed.

Ongoing Supports. In response to the summative evaluation open-ended question “What kind of ongoing support would better enable you to conduct future planning for individuals with disabilities?”, siblings reported six types of ongoing supports: handout or checklist of activities for future planning, ongoing monthly trainings, connections with agencies, ongoing sibling connections, reminders to update the LOI, and sharing resources. For example, a 31-year-old brother of an adult with ID reported that he wanted “connections with agencies” while a 24-year-old sister of an adult with ASD reported that “It would be great to have a group to check in with monthly to talk about goals and progress being made.”

Discussion

The purpose of this study was to pilot-test the STEP program to determine its outcomes and feasibility. Although several studies highlight the importance of siblings conducting future planning (Heller & Kramer, 2009), few intervention studies have been conducted with adult siblings of individuals with IDD (Hodapp et al., 2017; Lee & Burke, 2018). As one of the first studies to pilot a future planning intervention with siblings of individuals with IDD, this study provides important insight for researchers and practitioners. This study had five findings.

First, both quantitative and qualitative data suggested that participants had greater family communication after participating in the STEP program. Notably, family communication was required to complete the LOI, which may have facilitated this outcome. This study extends the literature by suggesting that a future planning instrument can facilitate family communication including adult siblings of individuals with IDD. This finding is especially poignant given that siblings often report being excluded from family conversations about future planning (Coyle et al., 2014; Heller & Kramer, 2009; Rawson, 2010).

Second, this study suggests that the STEP program may facilitate greater knowledge about adult disability services , which is critical to improve service delivery outcomes for adults with IDD (DaWalt et al., 2018; Heller & Caldwell, 2006). Notably, participants reported wanting more time to address adult disability services. Interestingly, although 55.56% of participants worked in a disability-related field (e.eg., special education, physical therapy, occupational therapy, social work), they acknowledged their limited knowledge about adult disability services . This finding is consistent with previous research suggesting the difficulty in learning about adult disability services (Arnold et al., 2012). In future iterations of the STEP program, there may need to be more time allocated to adult disability services.

Third, participants demonstrated increased empowerment with respect to the family and service systems. Empowerment is an important construct as siblings may feel disempowered across several contexts (e.g., feeling unable to voice their opinions in future planning; Heller & Arnold, 2010). Also, out of all of the outcomes measured in this study, empowerment may be the most powerful outcome to impact access to disability services. In a study about a parent advocacy intervention, participants demonstrated significantly increased knowledge, empowerment and advocacy; however, empowerment was the only outcome that strongly correlated with increased access to disability services (Taylor et al., 2017). Thus, the increase in empowerment among siblings of individuals with IDD may have important benefits for their brothers and sisters with IDD.

Fourth, participants demonstrated increases in disability connectedness. Although there are few interventions for siblings of adults with IDD (Hodapp et al., 2017), there are several interventions for parents of individuals with IDD (e.g., DaWalt et al., 2018; Taylor et al., 2017). In such interventions, it is common to use a cohort model to increase disability connectedness among parents of individuals with IDD (e.g., Volunteer Advocacy Program-Transition, Taylor et al., 2017). Indeed, the cohort model may offer greater benefits to participants due to the availability of peer support and increased connections within the disability community (Taylor et al., 2017). Given that siblings report wanting peer support (Arnold et al., 2012), this study suggests that offering an intervention via a cohort model may increase disability connectedness.

Finally, this pilot study suggested that the STEP program was feasible for siblings of individuals with IDD. Feasibility should be considered for sibling-targeted programs given that siblings are a hard-to-reach population. Indeed, siblings are often labeled as the club-sandwich generation as they often provide care for: aging parents, brothers and sisters with disabilities, and their own children (Hodapp et al., 2017). This study suggests that interventions can be feasibily conducted with siblings even though they may fulfill multiple caregiving roles.

Limitations

Although the findings of this current are promising, it is important to acknowledge its limitations. First, the sample was primarily female, White, highly educated, and worked in the disability field. Although consistent with previous sibling research (Hodapp et al., 2017), the lack of diversity is particularly problematic as siblings from non-dominant cultures (versus dominant culture) are significantly more likely to be caregivers (Sonik et al., 2016). For example, African American or Latino families have long-standing cultural traditions of having expansive care networks which may affect sibling caregiving (Dilworth-Anderson et al., 2005). Second, this study employed a single intervention group study (i.e., no control group). Because there was no control group, changes in the dependent variables cannot be attributed to the STEP program. Third, there could have been unaccounted for differences that impacted the results of this study. For example, future research may examine the differences on the use of distance versus in-person training.

Implications for Future Research

In future research, the STEP program should be refined according the findings from this study (e.g., adding more content about adult services) and those refinements should be tested via pilot studies. Fraser and Galinsky (2010) developed a five-step model for developing and testing an intervention: (a) develop a theoretical framework based on problems; (b) design intervention materials and measures; (c) confirm and refine program components by measuring efficacy; (d) examine effectiveness in a variety of settings; and (e) disseminate program findings and materials. Following this model, the STEP program could be strengthened based on the current findings. The revised STEP program should be tested with a bigger sample and more rigorous research design. Specifically, a RCT should be conducted to determine the effectiveness of the STEP program. An RCT can help determine causal inferences to understand the effectiveness of the STEP program. Specifically, by randomizing participants to an intervention and control group, an RCT can help attribute changes in outcomes to the STEP program.

In addition, researchers may consider comparing STEP sessions delivered in-person versus online. In some prior studies, participants learn the same amount of information regardless of whether their attendance was in-person or via videoconferencing (e.g., Shachar & Neumann, 2010; Taylor et al., 2017). In this study, we did not find a difference in outcomes with respect to modality (i.e., in-person attendance or videoconferencing). However, given the small sample size, future research should examine how distance learning may be impact future planning interventions with siblings of individuals with IDD.

Implications for Practice

Most participants reported that the STEP program was their first sibling-targeted training. Indeed, there are limited supports for adult siblings of individuals with IDD. The most well-known program for siblings is Sibshop (Meyer & Vadasy, 1994), which targets young siblings (i.e., aged 5-12). Thus, this study suggests that practitioners could deliver a training program (e.g., STEP program) to meet the needs of adult siblings of individuals with IDD.

Given the longer lifespans of individuals with IDD, it is necessary to address the roles of siblings. Unfortunately, many families have not included siblings in future planning (Heller & Arnold, 2010). The findings of this study contribute to the evidence about the outcomes and feasibility of a future planning intervention for siblings of individuals with IDD.

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Table 1.

Participant Demographics (*N* = 18)

Demographic	% (*n*)
Gender	
Female	88.9% (16)
Marital Status	
Single	94.4% (17)
Ethnicity	
White	72.2% (13)
Latino	11.1% (2)
Asian	16.7% (3)
Annual Household Income	
Less than $15,000	5.6% (1)
Between $15,001-$30,000	27.8% (5)
Between $30,001-$50,000	16.7% (3)
Between $50,001-$70,000	22.2% (4)
Between $70,001-$100,000	11.1% (2)
More than $100,001	16.7% (3)
Educational Background	
Some college	16.7% (3)
College graduate	38.9% (7)
Some graduate school	44.4% (8)
Gender of the brother/sister with IDD	
Male	50% (9)
Type of Disability of the brother/sister with IDD	
Intellectual disability	66.7% (12)
Learning disability	33.3% (6)
Autism spectrum disorder	27.8% (5)
Multiple disabilities	27.8% (5)

Table 2.

STEP session goals

Session	Goals	LOI activities
1. Sibling perspectives on future planning	(a) introductions (b) sharing the current state of future plans (d) identifying barriers to future planning (Lee & Burke, in press) (e) identifying the support needs of adult siblings of individuals with IDD (Heller & Kramer, 2009) (f) explaining the features of the LOI	Family stories, Family culture, Building relationships
2. Communication and Problem solving	(a) engaging in effective communication within families (Burke, Lee, Hall, & Rossetti, 2019; Lee, Burke, & Stelter, 2019) (b) learning problem-solving skills and applying it to case scenarios (DaWalt et al., 2018) (c) information on residential planning (Heller & Arnold, 2006) (d) a sibling panel	Housing, Post-secondary education, Work, Leisure
3. Legal and financial planning	(a) legal guardianship (Arnold et al., 2012; Brady et al., 2019; DaWalt et al., 2018) (b) the Supplemental Security Income (SSI)/Medicaid waiver (Arnold et al., 2012; Davys et al., 2015; Rawson, 2010) (c) the Family Medical Leave Act (Heller & Kramer, 2009; Hodapp et al., 2016)	Health care, Financial and Legal plans
4. LOI reflection and sibling well-being	(a) reflections about the LOI and future steps (b) Siblings as club-sandwich generations (Hodapp et al., 2016; 2017) (c) ways to connect to sibling organizations (Gauthier-Boudreault et al., 2017)	Dream and Nightmare, Goals for upcoming three months

Note. Information on employment, post-secondary, leisure and social planning was provided via workbook.

Table 3.

Time 1, Time 2, & Time 3 Survey Responses (N = 18)

	Time 1			Time 2			Time 3						
Item	50th	25th	75th	50th	25th	75th	50th	25th	75th	Chi-square	*p*	W[a]	Follow-up
1. Future Planning Activities	4	2	5	6	5	8	9.5	6	15	28.73	.00**	.80	T1 < T2 T1 < T3 T2 < T3
2. Adult Services Knowledge	5	3	5	9	8	9	8	7	9.25	27.85	.00**	.77	T1 < T2 T1 < T3
3. Disability connectedness	14	10	22	22	21	27	25.5	20.5	31.25	16.73	.00**	.47	T1 < T2 T1 < T3
4. Service system empowerment	35	31	44	43	38	48	44	37	48.5	15.64	.00**	.43	T1 < T2 T1 < T3
5. Family empowerment	46	36	54	50	43	54	50.50	44.25	54.25	13.77	.001**	.36	T1 < T2 T1 < T3
6. FAD Family communication	15	13	16	16	14	17	16	14.75	17	9.13	.01**	.25	T1 < T2 T1 < T3
7. FAD Family problem-solving	14	12	16	14	12	17	13.5	13	16	.31	.86	.00	-

Note. [a] W refers to Kendall's Coefficient of Concordance

* *p* ≤ .05. ** *p* ≤ .01.

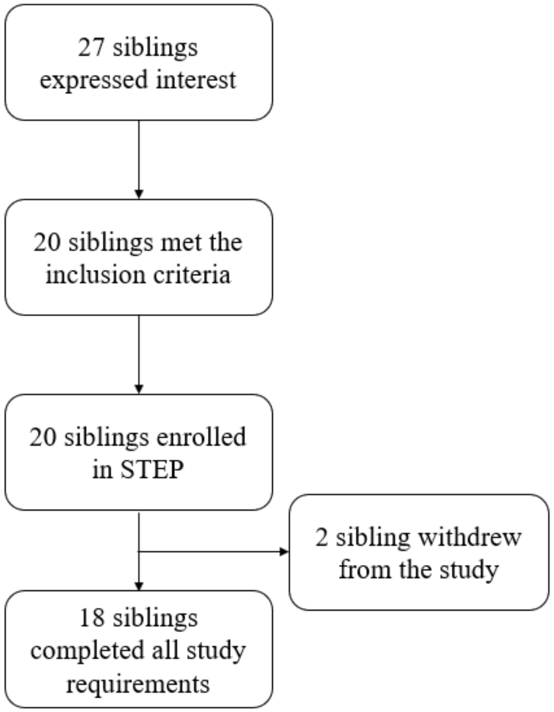

Figure 1. Participant recruitment, inclusion, and retention