

Supporting Adults with Intellectual and Developmental Disabilities and their Families in Future Planning and Advocacy

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Due to lifelong support needs and the structure of government benefits and services, planning for the future is particularly important for individuals with developmental disabilities (I/DD) and their families (Heller & Factor, 1993; Freedman, Krauss, & Seltzer, 1997). Key aspects of planning that typically need to be addressed include future living arrangements, guardianship and less restrictive alternatives, financial planning, future vocational and recreational desires, and general lifestyle choices. Without adequate plans and supports in place, individuals with developmental disabilities can face unfortunate situations of emergency placements in inappropriate settings and inadequate financial and legal safeguards when primary caregivers can no longer provide care.

Despite these concerns, research indicates that fewer than half of families make plans for future living arrangements (Heller & Factor, 1993; Freedman, Krauss, & Seltzer, 1997). Families face many systemic and emotional barriers to planning (Heller & Factor, 1991). Furthermore, many families do not discuss future plans with their relatives with developmental disabilities or other family members (Heller & Factor, 1994; Smith & Tobin, 1989).

While the need to support families in future planning is well documented, the best ways to do so are still unclear. Merely providing legal and financial information has not proven to be effective in promoting actual planning outcomes (Preston & Heller, 1996). Psychoeducational and peer support intervention may be more effective in facilitate planning (Smith, Majeski, & McClenny, 1996). However, while several future planning projects have been developed across the United States, little is known about approaches taken and very little empirical evidence exists as to their effectiveness in promoting planning outcomes.

Study Purpose and Objectives

This project addresses the following research questions:

1. What are the current best practices for fostering futures planning among persons with developmental disabilities and their families?
2. What is the effectiveness of a peer support family future planning intervention for adults with developmental disabilities and their families?

Sample Population and Methodology

A. Identification of Best Practices

Sample. Model future planning projects within the US and Canada were identified through the internet and phone calls to UCEs and Arc chapters.

Study methodology. Telephone interviews with project coordinators of future planning training projects were conducted and requests made for the training materials.

Data analysis. Exploratory, descriptive information was compiled on the types of approaches used. Findings were published and used to construct the intervention.

B. Intervention Study

Sample. Families were recruited for the intervention from 6 community service provider agencies in Illinois serving adults with developmental disabilities. One-day legal/financial training sessions were hosted where attorneys covered the topics of government benefits, guardianship and less restrictive alternatives, and special needs trusts. Families interested in the intervention were randomly assigned to either the intervention or control group. Families were also recruited for the control group through one-day legal/financial sessions conducted at two additional randomly selected agencies where the intervention was not offered.

The final sample consisted of 56 families who completed both pre-test and follow-up surveys –29

families who participated in the intervention and 27 families who were part of the control group. There were no significant differences between the control or intervention group on any demographic variables. Overall, for the entire sample (N = 56) the average age of primary caregivers was 64 years of age, with ages ranging from 44 to 85. The average age of individuals with DD was 37 years of age, with ages ranging from 18 to 58. Twenty-five percent of the sample was African-American and 14.3% was Hispanic.

Study methodology. The intervention consisted of 5 additional workshops, following a one-day legal/financial training session conducted by an attorney. The intervention adopted person-centered planning tools and focused on the development of a letter of intent.

Pre-test and one-year follow-up surveys were conducted with the 56 family caregivers in the control and intervention groups. Measures included future planning activities (special needs trust, residential planning, guardianship, and letter of intent), caregiving appraisals (burden, satisfaction, and self-efficacy), discussion of plans with individuals with developmental disabilities, and choice-making of individuals with developmental disabilities. Pre-test and follow-up interviews were also conducted with 18 individuals with developmental disabilities who participated in the intervention and were capable of participating in an interview. Measures included curriculum knowledge, unmet needs for leisure activities, and life satisfaction.

Data analysis. McNemar tests were conducted to compare the numbers of families who had completed future planning activities over time. McNemar tests indicated that families in the intervention group developed a letter of intent,

established a special needs trust, and took action on residential planning over time, $p < .05$.

Analyses of variance compared the groups over time on the following measures (caregiving burden, caregiving satisfaction, caregiving self-efficacy, discussion of plans with individuals with developmental disabilities, and daily choice-making of individuals with developmental disabilities). Compared with the control group, caregiver burden significantly decreased over time for caregivers in the intervention group, $F(1,54) = 7.97, p < .05$. There were no significant differences between the intervention and control group over time

on caregiving satisfaction or caregiving self-efficacy.

Discussion of future plans with individuals with developmental disabilities significantly increased over time in both the intervention and control groups.

Compared with the control group, choice-making of individuals with developmental disabilities significantly increased over time for families in the intervention group, $F(1,51) = 6.20, p < .05$.

The most frequently identified barriers to future planning were explored. The top barriers identified were: 1) difficulty trusting the service system and professionals (37.5%); 2) difficulty affording financial costs of attorney (35.7%); 3) difficulty finding helpful contact persons within the service system (33.9%); 4) emotional barriers fighting the service system (32.1%); and 5) emotional barriers involved with thinking about own mortality (32.1%).



McNemar tests were also conducted on outcome measures for the 18 individuals with developmental disabilities who completed pre-test and one-year follow-up interviews. There were no significant differences on curriculum knowledge or life satisfaction. However, there was a significant decrease in the number of unmet needs for desired leisure activities.

Implications for Research and Practice

Information on projects supporting families in future planning across the United States and Canada was compiled and published in a policy brief for the *National Center for Family Support* (Heller, 2000) and a book chapter (Sterns, Kennedy, Sed, & Heller, 2000). This information was also used to develop an intervention to support families and individuals with developmental disabilities in future planning. Key aspects included peer support and inclusion of individuals with disabilities. The intervention significantly contributed to families completing future planning activities, decreased caregiving burden, decreased unmet leisure needs and increased choice-making of individuals with developmental disabilities.

The curriculum titled *The Future is Now* (DeBrine, Caldwell, Factor, & Heller, 2003) was produced. This curriculum is available through the RRTCADD Clearinghouse and has been used by service provider agencies to conduct additional intervention. We also collaborated with the Illinois Department on Aging (Administration on Aging Senior Caregiver Initiative) to provide this curriculum to senior caregivers across Illinois. In addition to the curriculum, a resource guide was produced with input from families in the intervention (Caldwell, Lopez, DeBrine, Factor, & Heller, 2003). Over one hundred and fifty copies of the resource guide have been distributed to families and service providers. The resource guide is available to order or can be downloaded for free on the RRTCADD website.

Articles about the project were published in newsletters (ADD/Vantage and American Association on Aging). Results of the intervention are currently being submitted to a peer-reviewed journal for publication.

The project has also received considerable media attention. One of the families who participated in the project did a television interview with Tamar Heller that appeared on the local Chicago news. Several newspaper articles have been done on the topic of aging family caregivers and future planning, referencing Tamar Heller and the RRTCADD. This media attention has raised awareness of aging caregivers and extensive waiting lists for residential services.

Finally, the project included individuals with DD in meaningful ways throughout the research. An unexpected outcome of the project was the establishment of a self-advocacy chapter through collaboration with People First of Illinois. In addition to including people with disabilities in future planning, it is also important to include siblings, who most often assume future caregiving roles. This project has led to the development of the new RRTCADD project to promote the inclusion of siblings in future planning.

Publications and Products

Debrine, E., Caldwell, J., Factor, A., & Heller, T. (2003). *The future is now: A future planning training curriculum for families and their adult relatives with developmental disabilities.*

Caldwell, J., Lopez, E., DeBrine, E., Factor, A., Heller, T., & Ennis, D. (2003). *Future planning resource guide for families and adults with developmental disabilities in Illinois.*

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