

## Supporting Aging Caregivers and Adults with Developmental Disabilities in Future Planning

“I met with an attorney and set up a special needs trust.”

“My daughter benefited from walking through the process. She knows what will happen if something should happen to mom and dad and we could no longer care for her.”

“I finally placed my daughter on a residential waiting list.”

### Need for Future Planning

Over 75% of people with developmental disabilities live at home with their families. The primary caregiver in 25% of these homes is over the age of 60. Future planning is particularly important for families with relatives with developmental disabilities. Key aspects of planning typically include future living arrangements, guardianship and less restrictive alternatives, financial planning, future vocational and recreational desires, and general lifestyle choices. While planning is important, there are many informational, psycho-social, and systemic barriers that families face. Without adequate plans and supports 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.

### The Intervention

The Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities developed an intervention to help support individuals with developmental disabilities and aging caregivers in planning for the future. The intervention was based on a model of peer support. Families supported each other through a series of five small-group sessions following a one day legal and financial planning session. Individuals with developmental disabilities were included in the five additional sessions through materials accommodating their level of understanding and the use of co-facilitators with developmental disabilities. The five sessions included the following topics:

- Taking the First Step to Planning
- Relationships and Support Networks
- Residential and Housing
- Work, Retirement, and Leisure
- Identification of a Future Caregiver or Key Succession Person

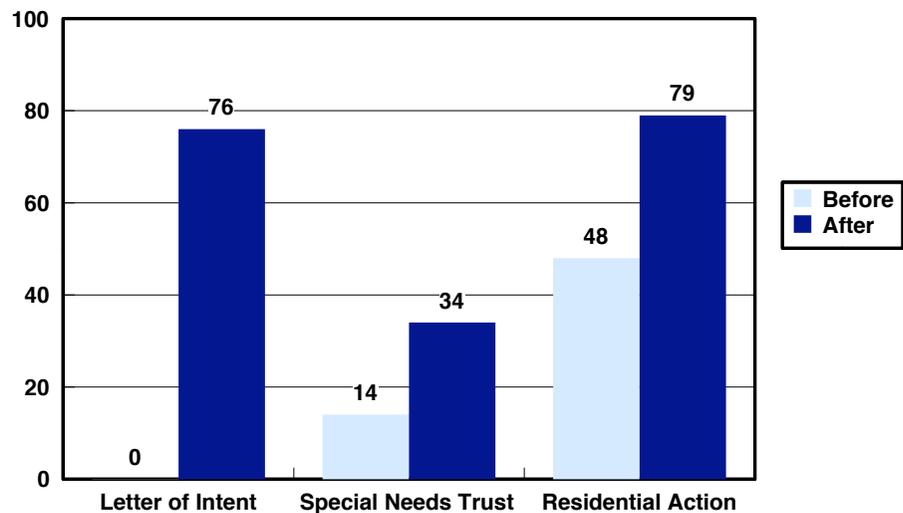
Through the five sessions families worked on a letter of intent, which is a non-legal document that captures family desires and goals for the future.

## Outcomes of the Intervention

Pre-test and one-year follow up surveys were conducted with 29 families who participated in the intervention and 27 families in a comparison group. Families were recruited from collaborating community agencies and randomly assigned to groups, primarily based on agency. The comparison group attended the one-day legal/financial session but not the 5 additional sessions.

The intervention significantly contributed to families completing a letter of intent, developing a special needs trust (a trust which protects government and disability benefits), and taking action on residential planning.

**Future Planning Actions  
(Percentage of Families)**



In addition, the intervention also contributed to the following outcomes:

- Decreased caregiver burden
- Increased choice-making of individuals with disabilities
- Increased discussion of plans with individuals with disabilities

In collaboration with the Illinois Department on Aging the future planning intervention has been replicated with families across Illinois. The curriculum entitled The Future is Now is now available through the RRTC on Aging with Developmental Disabilities.

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To order The Future is Now curriculum contact:  
Clearinghouse on Aging with Developmental Disabilities  
RRTC on Aging with Developmental Disabilities:  
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Website: [www.uic.edu/orgs/rrtcamr](http://www.uic.edu/orgs/rrtcamr)

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“I should have done this 15 years ago!”

“The workshops were an eye-opener!”

“We are sharing information with parents of younger children to encourage them to think about a future plan for their child – Time slips by so quickly.”



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