

The Importance of Future Planning: Supporting Aging Caregivers and Individuals with I/DD

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What is Future Planning?

Creating a plan to help guide a person with I/DD to lead an independent life.

[Begin →](#)

Not Sure Where to Start?

Planning ahead can be overwhelming. Get tips on how to get started.

[Begin →](#)

Get Started!

Learn more and begin to plan.

[Begin →](#)

Urgent Need

Need urgent help? Start here instead.

[Begin →](#)

[See how others have planned →](#)

Why?

- There are 600,000 -700,000 families in the U.S. in which an adult with I/DD is living with aging family members.
- All too often, there is no plan in place for the individual's future.
- The Center for Future Planning's objective is to reach out to families that have no plan in place and by providing reliable information, resources, and practical assistance to encourage and support those families to create future plans.

Barriers

The launch of the Center for Future Planning website is a step towards breaking down the barriers that keep families from planning for the future.

The barriers include:

- Lack of Information
- Difficulty addressing emotional issues related to caregiver's mortality
- Unavailability of appropriate services
- Difficulty of affording services of attorneys and other professionals

Website

The website will provide information on future planning

- Tailored to different users
- On the steps families need to take to create a plan
- Using supportive and person-centered language



*For people with intellectual
and developmental disabilities*

Not Sure Where to Start?

Creating a person-centered plan for the future can be difficult, but it is possible. Future plans help families and people with I/DD establish their vision and roadmap for the future.



Parent



Person with I/DD



Sibling



Staff at Chapter of The Arc



Other Family / Friend



Professionals

Achieve with us.®

See How Others Have Planned

A Parent's Perspective: Kandi's Independent Living

Ginger, mother of Kandi

Daily Activities

Future Planning 101

Parent



I've always been someone who has wanted things to be better - not only for my daughter but for my community in general. When I first heard about future planning, it made sense to me that as parents, we need to plan for the future. Thinking and planning ahead will help your son or daughter achieve his/her highest potential.

My daughter, Kandi, is a great example of living an independent and good life. Kandi is a 50-year-old woman with moderate intellectual disabilities who lives and works in the community.



For people with intellectual
and developmental disabilities

Get Started!

Ready to start a person-centered plan? Learn more on how to create a plan for the future in all areas of life.



Expressing Wishes for the Future



Deciding Where to Live



Financing the Future



Establishing Daily Activities



Supporting Daily & Major Life Decisions



Making Social Connections

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Contact Us

This is the beginning.

The Center for Future Planning will be developing additional resources and supports.

Please provide us your ideas and feedback.

Email: futureplanning@thearc.org



*For people with intellectual
and developmental disabilities*

Tamar Heller

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UIC Department of Disability
UNIVERSITY OF ILLINOIS and Human Development
AT CHICAGO
COLLEGE OF APPLIED HEALTH SCIENCES

Demographic and Policy Context for People with DD and Their Families

- Longevity revolution
- Rebalancing from institutions to group homes and to supported living
- Increase in family support
- Increase in self-directed supports
- Broader changes in state DD service systems toward managed care

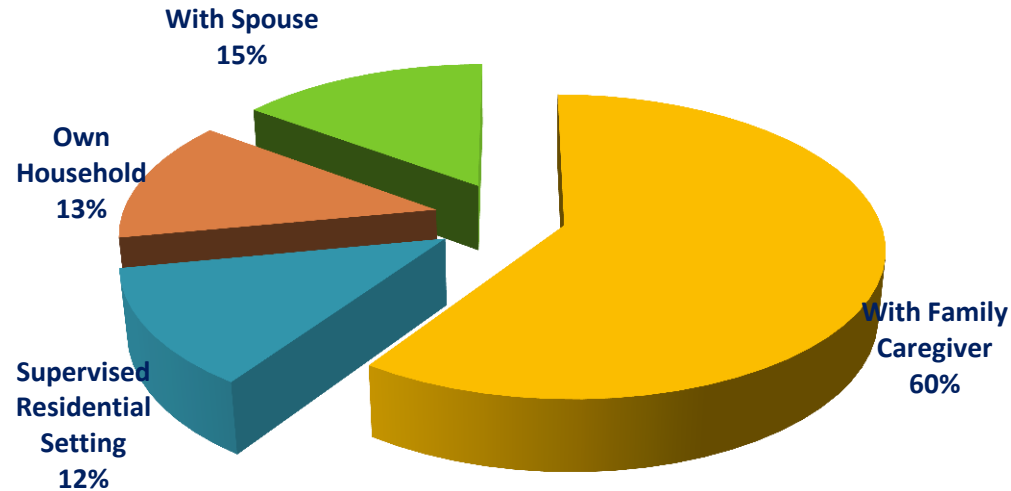
Estimated Number Of IDD Caregiving Families Compared To Families Supported By State IDD Agency Funds: 2011

State	Total IDD Caregiving Families	Families Supported by I/DD Agencies		% of Families Supported
UNITED STATES	3,513,224	467,958		13%

Source; Braddock et al, Coleman Institute and Department of Psychiatry, University of Colorado, 2012.

Emerging Challenges: Demographics

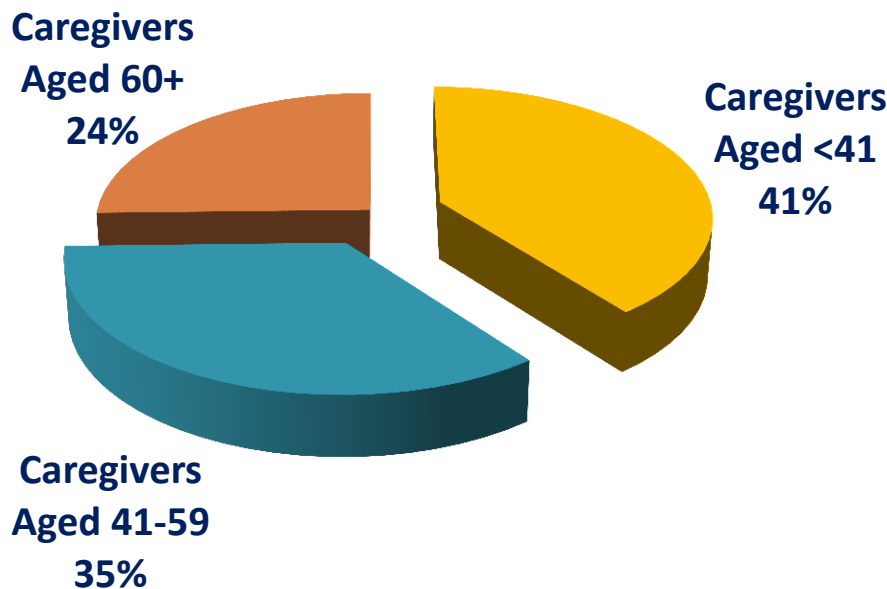
Where People Live: US, 2011



Source Braddock, Hemp, & Rizzolo, 2012

Emerging Challenges: Demographics

Age of co-residing caregivers of people with I/DD,
2011 (n= 3,513,224, 72% of people with I/DD)



Source: Braddock, Hemp, & Rizzolo, 2012

Need to Plan for Future Needs

- Many families do not make plans and are unaware of legal and financial options
- Lack of collaboration between aging and disability service system
- Many families have avoided contact with formal disability services
- Results in continued worry about the future, stress, emergency placements, poor transitions
- Siblings left to scramble
- Poor financial plans

Well Considered Plans

- Person centered
- Address the needs of person with disabilities and family
- Consider steps need to take
- Help family discover new possibilities
- Better chance of realizing family hopes!

Barriers to Planning

- Anxiety about mortality
- Unaware of options
- Lack of resources and options
- Unaware of possibilities
- Afraid to “burden” siblings
- Restricted social network

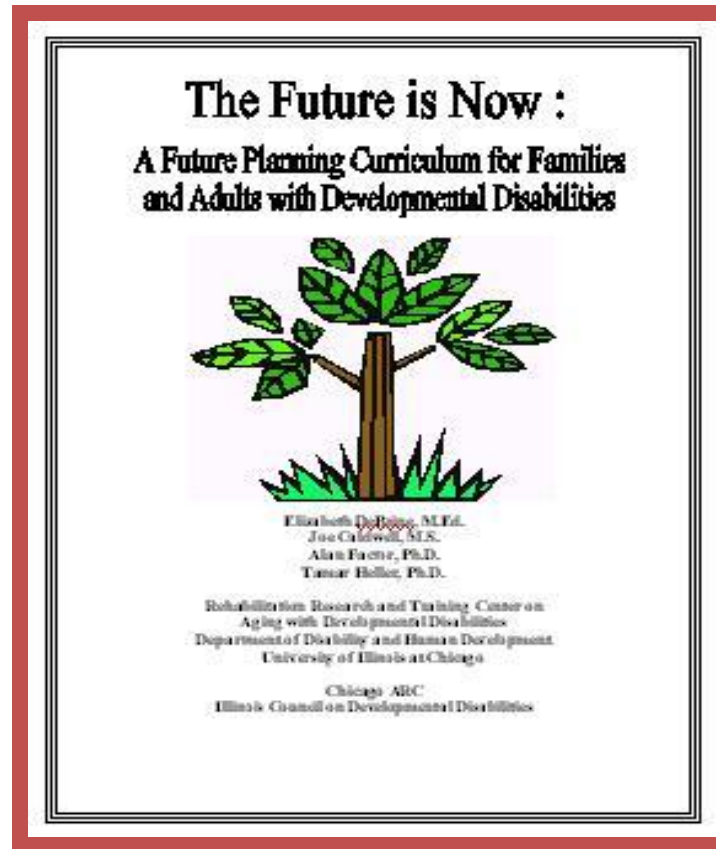
What do Families Need?

- Identify concerns and share
- Gather helpful information
- Network with other families
- Discuss and negotiate within family
- Advocate for services and supports

THE FUTURE IS NOW CURRICULUM

(Factor et al., 2012); (Heller & Caldwell, 2006)

Visit www.rrtcadd.org



Curriculum Overview

- Legal/Financial Planning Session (full day)
- 5 Additional Workshops
 - 2.5 hours each
 - 2 to 4 weeks apart
 - Approximately 5 - 15 families
 - Attend with relatives with ID
 - Simultaneous workshops geared to level of understanding
 - Use co-facilitators with ID and families
- Development of Letter of Intent

Workshop: Family Caregivers

- 34 Family Caregivers and 28 Individuals with Disabilities in Monthly Workshops



Workshops for Individuals with DD



What Did Families Want?

- Goals of Families
 - Special needs trust (most frequent goal of family)
 - Community job (most frequent goal of individuals with disabilities)
 - Discuss letter of intent with other family
 - Revise will
 - Talk to people I would like as guardian
 - Look into housing options
 - Support son to attend People First meetings
 - Support son with interest in dating

Dreams & Nightmares

Dreams

“My child will live a safe and healthy life, in the perfect placement, with relationships maintained”

“My hope for my daughter is that she be part of the community that meets all her needs, and calls her out, as the person she was created to be.”

“My son dies one minute before I do”

Nightmares

“Fear of becoming ill myself”

“The finances, waiting lists, and the person I have identified to follow me dies too”

“He dreams so big and it’s a nightmare that I can’t fulfill the dream”

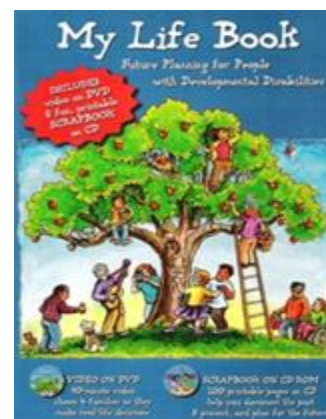
Future is Now Outcomes

(Heller & Caldwell, 2006; Factor et Al., 2012)

- Randomized one year –pre-post test
- Key outcomes
 - Developed Special Needs Trust
 - Made residential plans
 - Developed a Letter of Intent
 - Caregiving burden decreased
 - For adult with ID more daily choice making and fewer unmet leisure needs

My Life Book

- My Life Book: Future Planning for people with developmental disabilities (2004) IRIS Media, Inc.
- DVD, CD, and activity book
- Video follows four families attending a future planning class and begin the process of making important life decisions
- Visit www.lookiris.com



Future Care Planning: A Roadmap for Family Caregivers

- On line resource for family caregivers to help them engage in conversations and develop future plans for and with their relative with IDD
- http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/publication/CAREGIVING_Roadmap_021010.pdf

Taking Charge of Your Supports

- Awareness of preferences and options
- Making choices
- Participating in a PATH Process
- Using the Self-Directed Waiver to attain goals

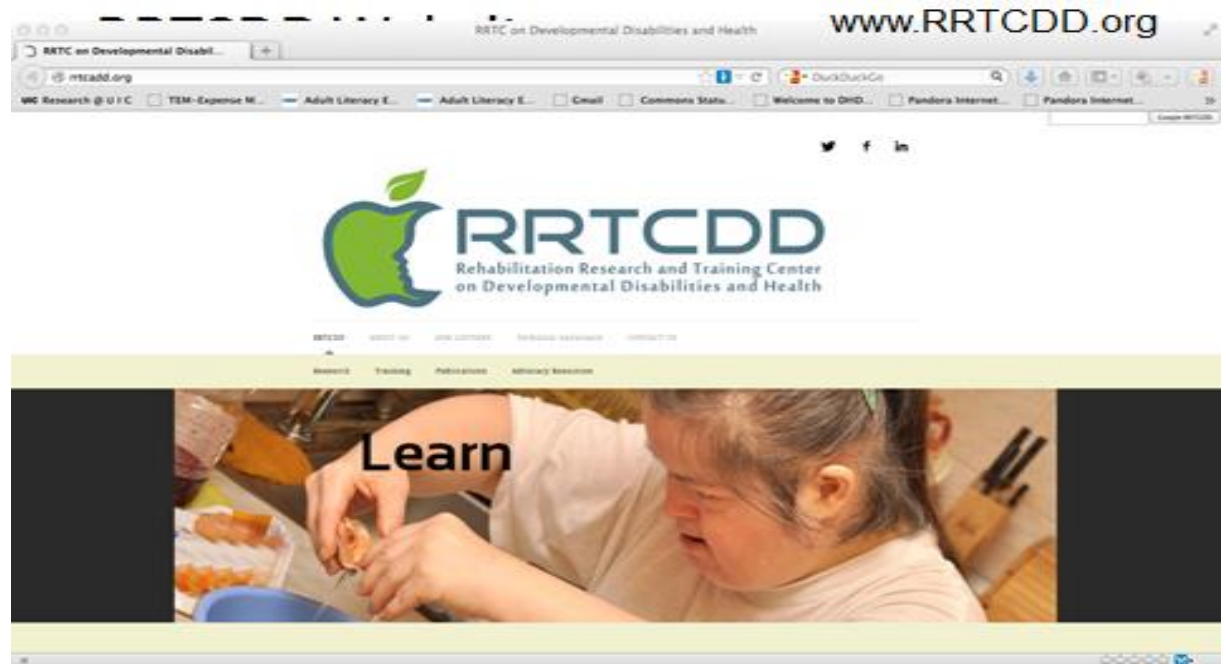


Contact us

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Challenges that Disability Organizations Face when Supporting Families with Aging Caregivers

Nancy Murray

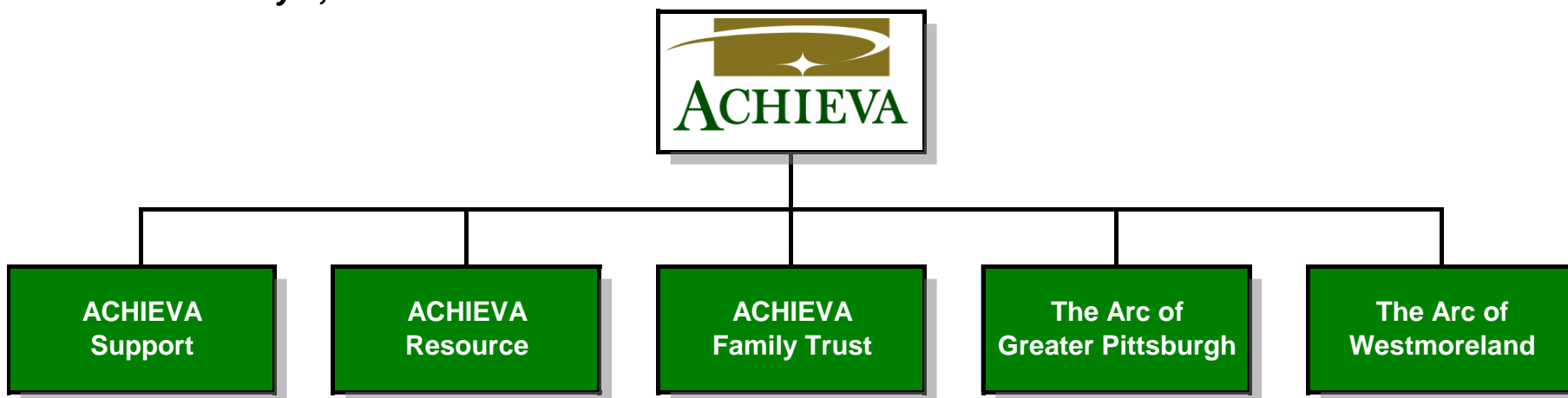
President, The Arc of Greater
Pittsburgh/ACHIEVA

Topics

- Introduction to ACHIEVA
- Who are aging caregivers
- The numbers
- Issues faced by aging caregivers
- Challenges in supporting aging caregivers
- Solutions to these challenges

ACHIEVA Family of Organizations

Organizational Chart
as of July 1, 2010



Who are aging caregivers?

They are generally considered to be:

- parents over the age of 60
- who provide life-long care for an adult child with a disability within the family home, well past the age that parents of children without disabilities provide care.

Aging Caregivers

Historically, it was the norm for many parents to survive their child with an intellectual disability.

However due to medical advances, and people living in our communities (rather than institutional settings), people with disabilities are living longer. Therefore this increases the likelihood of older adults with intellectual disabilities outliving their parents.

Aging Caregivers

Although aging family caregivers of adults with intellectual disabilities share similar challenges with other caregivers, they face distinctively different circumstances from caregivers of persons that have developed illnesses or disabilities later in life.

The Numbers

- There are approximately 200,000 people with intellectual disabilities in Pennsylvania and 71% (143,000) of them live with their families.
- Of the 143,000 families, only 25,000 receive family support services from the system.
- 29% (41,470) of these families have aging caregivers.

Braddock et al., Coleman Institute and Department
of Psychiatry, University of Colorado, 2013.

Issues Faced by Aging Caregivers

- Physical
- Psychological
- Social
- Financial

Physical Issues

The stress associated with caregiving can lead to adverse impacts on one's physical wellbeing in clinically measurable ways, including:

- elevated blood pressure,
- greater risk of developing cardiovascular disease,
- physical exhaustion,
- higher susceptibility to infections and illness, and
- higher risk of mortality

Psychological Issues

Decades of caregiving can lead to adverse impacts on one's psychological and emotional wellbeing, including:

- an increased risk of developing depressive disorders,
- increased feelings of stress,
- lower levels of self-efficacy and
- lower levels of subjective well-being.

Social Issues

In addition to physical and psychological implications, caregivers may experience issues with their relationships with other family members and friends:

- the time spent on caregiving may result in exhaustion and/or a lack of time to spend with others,

Social Issues

- often, caregivers report taking fewer, if any, vacations,
- they may also engage less in leisure activities.
- over time, as social contacts lessen and participation in social activities declines, caregivers are at greater risk for increasing social isolation.

Financial Issues

- caregivers often have to leave the workforce to care for an adult family member with a disability,
- or, caregivers have to work part-time, rather than full-time, to provide care, and
- the results include less family income, fewer employer-provided benefits, and reduced or no retirement savings.

Financial Issues

- financial resources needed to pay other caregivers,
- financial resources for services and items not covered by government benefits or insurance:
 - transportation
 - specialized equipment
 - respite
 - medications
 - home modifications
 - adaptive equipment

Challenges in supporting aging caregivers

- As parents and their adult children with disabilities grow older together, they develop mutually dependent relationships.
 - companionship
 - sharing household chores
 - financially sharing household expenses

Challenges

- Families of people with disabilities may face increasing competition for social service funding.
 - increasing number of aging baby boomers
 - shrinking state budgets
 - waiting lists for desperately needed services

Challenges

- Families of adult children with disabilities are frequently compound caregivers
- This results in them experiencing
 - even more stress and exhaustion
 - fewer financial resources
 - competing demands for their time

Challenges

- Oftentimes it is difficult to locate aging caregivers.
 - socially isolated
 - gave up on the “system” years ago
 - tend not to utilize technology

Challenges

- Aging caregivers are worried about:
 - who will care for their family members when they no longer can do so
 - where and with whom their family members will live
 - who will advocate for them
 - what services will be available for them

Challenges

- Although parents know they need to plan for the future, many experience sadness, fear and sometimes a paralysis when it comes to future planning.
- It is very difficult to think about the day when you can no longer care for your child and you have to leave the advocacy and the care to someone else.

Solutions to these challenges

- Need to provide funding for family support services that are designed to improve families' ability to care for their family member with an intellectual disability in the family home:
 - home modifications
 - in-home and out-of-home respite
 - emotional support

Solutions

- Ensure that in households where an aging caregiver is caring for an adult with an intellectual disability, aging and disability support coordinators are working as a team to provide all of the services that the family requires, such as:
 - meals on wheels
 - transportation to a senior center for respite and socialization
 - day supports for the adult with the disability
 - visiting nurses

Solutions

- Support aging caregivers to view future planning as an on-going process, that it will give them peace of mind and that they do not have to do this alone
- Include other family members, a member of the clergy, an attorney, another parent of a child with a disability as a peer supporter, a financial planner and/or trusted friend.



Next Webinar:

Wednesday, December 10, 2014, 2:00-3:00 PM Eastern
First Steps in Future Planning: Letters of Intent and Financial Planning

If you have any questions, please contact us at
futureplanning@thearc.org