

Family Future Planning and Aging Adults with Intellectual and Development Disabilities

Webinar series: July 13, 20, & 27th

**Supported by the Texas A & M and
Texas Council for Developmental Disabilities**

**Tamar Heller and Katie Arnold
University of Illinois Chicago**



Webinar 1: Family Future Planning: Taking the Big Step to Plan

July 13, 2022

**Tamar Heller and Katie Arnold
University of Illinois Chicago**

Life-Long Impact

- ▶ Middle and older adult family caregivers of adults with IDD often provide lifelong care
- ▶ “Wear and tear” (Johnson & Catalano) ?
- ▶ Adaptation over time (Townsend)?

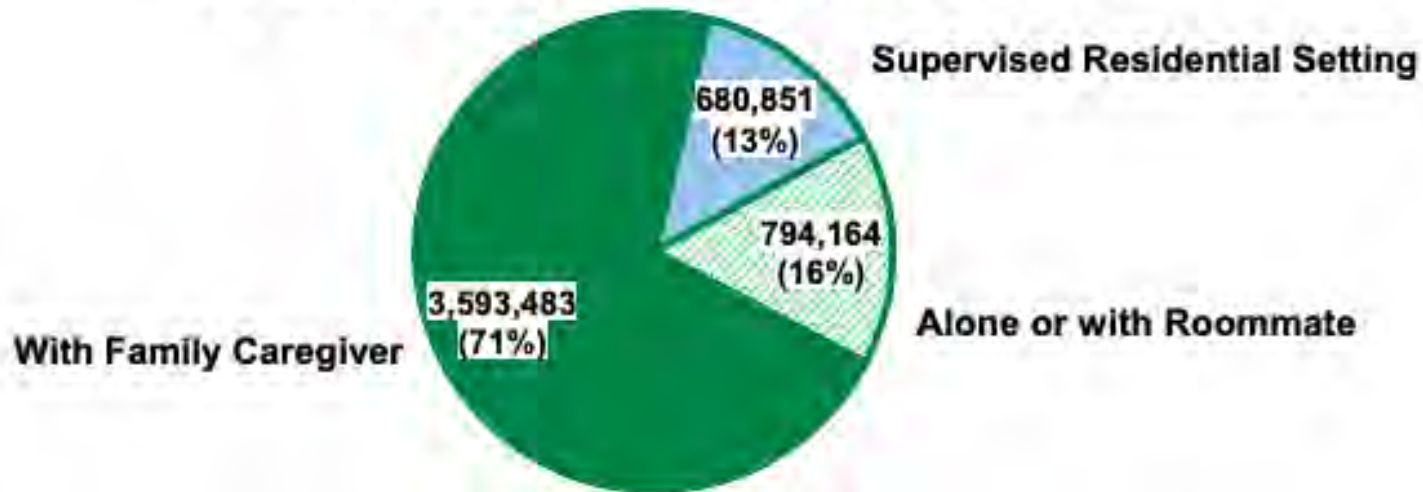


Families and Long-Term Services and Supports (LTSS)

- ▶ More likely to live with parents
- ▶ Often need LTSS life-long
 - ▶ 47,695 in TX in LTSS
 - ▶ Long waiting lists (increase from 43,479 in 2004 to 217,786 in 2017) in TX
- ▶ Families and persons with disabilities need to engage in future planning

Most people with IDD Live with Family

ESTIMATED NUMBER OF INDIVIDUALS WITH IDD BY LIVING ARRANGEMENT: FY 2015

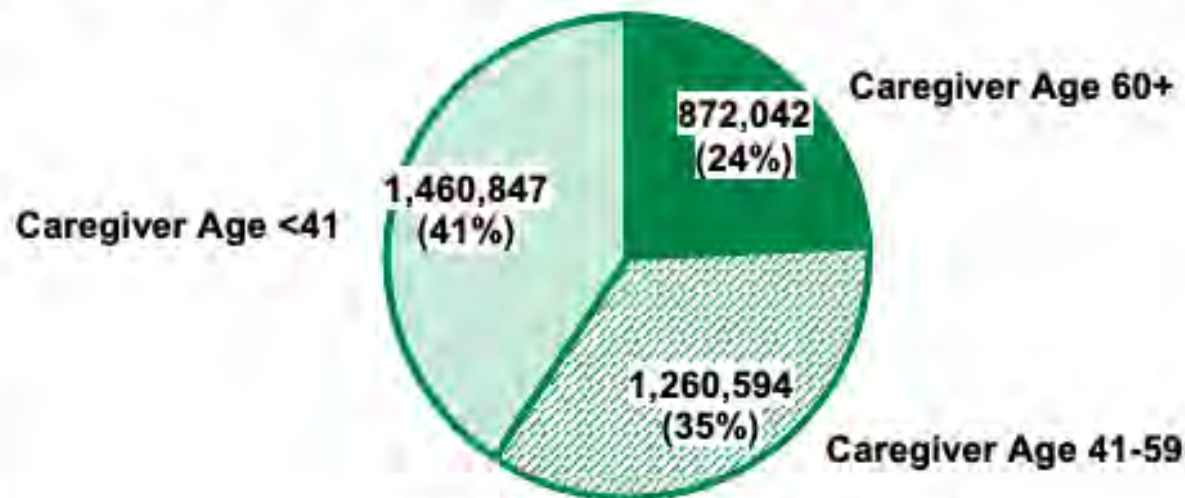


TOTAL: 5,068,498 PERSONS

Braddock et al. 2010, based on Fujiura 2008, 2012

Family Caregivers are Aging

ESTIMATED NUMBER OF INDIVIDUALS WITH IDD BY AGE GROUP LIVING WITH FAMILY CAREGIVERS: FY 2015



TOTAL: 3,593,483 PERSONS

Braddock et al. 2016, based on Fujiura 2008, 2012

Life-Long Impact for Families

- ▶ Experience chronic stress and risk of poor mental health and QOL
- ▶ Greater risk for some underserved groups
- ▶ Difficulties as person with IDD and parents age
- ▶ Caring also has its positive aspects

Caregiving Impact: Economic

- ▶ Often results in reducing work hours, changing jobs, stopping work entirely, and taking a leave of absence (NAC, 2009)
- ▶ Caregivers of individuals with IDD less likely than non-caregivers to be employed, miss more days of work (Bronheim, Goode, & Jones, 2006), and have less income (Parish, Seltzer, Greenberg, & Floyd, 2004)
- ▶ Families of individuals with disabilities have lower savings leading to less for retirement (Metlife, 2011)
- ▶ Economic losses greater for racial/ethnic minority groups (AARP, 2013)

Impact on Families: Health and Social

- ▶ Parents of adults with disabilities have higher stress, depression, anxiety, and physical health issues (Vanegas & Abdelrahim, 2016, Lunsky et al., 2014)
- ▶ Greater impact when:
 - ▶ need for more behavioral support, complex health care needs, and difficulty getting services
 - ▶ compound caregivers (Wang et al, 2022)
 - ▶ racial/ ethnic minorities (Magana & Smith, 2006)
- ▶ Social networks more restricted (Seltzer et al., 2011)
- ▶ Impact changes over time

Impact on Caregiving Appraisal

- ▶ Future planning and community involvement related to more caregiving satisfaction and caregiving self-efficacy, respectively.
- ▶ Challenging behaviors and poor health of adult with autism related to greater caregiving burden. (Burke & Heller, 2016)

Positive Aspects

- ▶ Can be source of fulfillment and meaningfulness
- ▶ Some report better mental health, life satisfaction (Grossman & Webb, 2016)
- ▶ Reciprocity in caregiving, especially to aging parents; people with disabilities are also caregivers (Heller & Factor, 2008; Arnold, 2022)
- ▶ Resilience among caregivers associated with positive social support, higher QOL, self-efficacy, and problem and meaning-focused coping styles (Chakurian, 2021)

Family Ties: Siblings as Longest Lasting Relationship



Siblings as the Club Sandwich Generation



Impact on Siblings

- ▶ Sisters more involved in care of adult siblings with IDD
- ▶ As get older sibs more involved in care
- ▶ Negative factors: family history of depression, especially mother, and stressful events
- ▶ Positive factor is family support
- ▶ Sibling well being and close relationship bi-directional
- ▶ Less positive relationship if more challenging behaviors (Orsmond & Fulford, 2018)

Impact on Siblings

- ▶ In comparison with siblings of adults with Down Syndrome, siblings of adults with autism had:
 - ▶ Less contact with sibling
 - ▶ Less positive relationship
 - ▶ Worse relationship with their parents
 - ▶ Worse health

-Heller & Arnold, 2010

Sibling Supports

- ▶ Sibling Leadership Network: Advocating for and with our siblings
 - ▶ www.siblingleadership.org
 - ▶ 27 state chapters
- ▶ Sibnet
- ▶ Siblings FORWARD (Focusing on Relationships, Well-Being, and Responsibility Ahead) (Orsmond, 2022)



Interaction of Aging and IDD in Life Transitions

Development of chronic health conditions



Changes in family caregiving and supports



Retiring from employment



Receiving end of life care

Worry about Future Care

- ▶ “I wish my child dies 4 minutes before I do”

Four Bodies in Elmhurst

Why would an 82-year-old man kill his son, his daughter, his wife and himself?
Photo by Jeff Himmelman, Dec. 2, 2015 /
New York Times



Experts say probation understandable for woman who killed disabled daughter

Litz pleaded guilty to involuntary manslaughter in the death of her daughter.

Photo by Stacey Wescott / Chicago Tribune

Bonnie Litz and her attorney.



Issues in Adulthood and Aging

- ▶ Many adults with ASD continue to live at home and are unemployed or underemployed with no pensions
- ▶ High rates of medical and psychiatric conditions (can stabilize, reduce, or increase)
- ▶ Difficulty finding doctors with needed expertise
- ▶ Reduction in some behavioral symptoms
- ▶ Some earlier age- related chronic conditions (due to medications, health care, and health behaviors)
- ▶ Need to address end of life issues
- ▶ Challenge for aging parents who have fewer supports
- ▶ Siblings take on greater roles

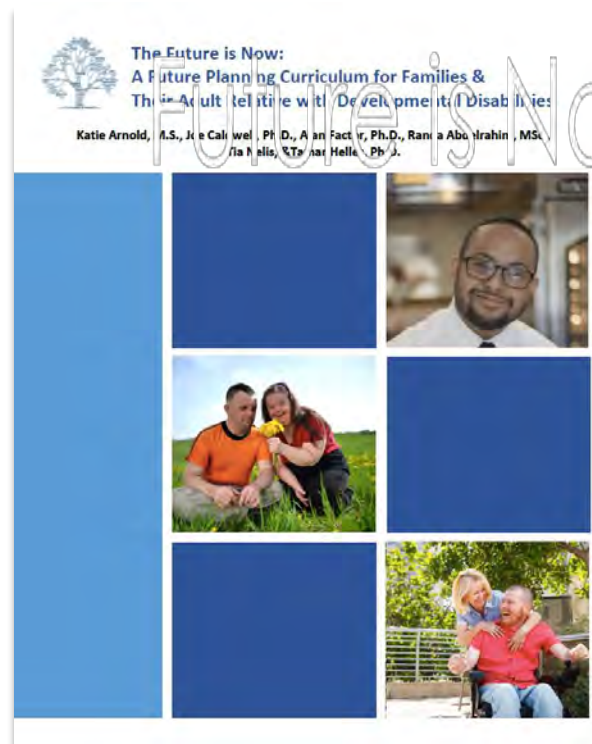
Unmet Family Support Needs: Adulthood and Aging

- ▶ The role of families more formalized in schools unlike adult systems of care
- ▶ Among families of people with disabilities who wanted a specific service over two-thirds had an unmet need for support groups (71.7%), meal services (72.4%), and respite (73.3%). Nearly half had an unmet need for assistive technology (46.8%), home healthcare (50.0%), home modifications (59.5%), and training or education for future planning (62.8%) (Crabb, Owen, & Heller, 2021).

Need to Plan for Future Needs

- ▶ Many families do not make plans and experience barriers:
 - ▶ Unaware of legal and financial options
 - ▶ Fears for the future and unknown
 - ▶ Difficulty identifying caregiving support for the future
 - ▶ Difficulty in initiating the process
 - ▶ Have little contact with and mistrust formal disability services
 - ▶ Lack of collaboration between aging and disability service system
 - ▶ Age-related needs and daily demands
- ▶ Planning is related to resources, ways of coping, and options in the community

Future is Now Curriculum



Development and Purpose of The Future is Now

- ▶ Overall goal: Families make future plans
 - ▶ Develop goals related to future plans
 - ▶ Develop letter of intent
 - ▶ Increase advocacy for supports
- ▶ Distinct Facilitators Guide and Workbook for:
 - ▶ Families and
 - ▶ People with disabilities



Overview of the Curriculum

Introductory session with overview on Future Planning and legal/financial planning information.

1. Taking the Big Step
2. Building Relationships and Self-Determination
3. Supporting Community Living
4. Choosing Education, Work and Retirement Options
5. Keeping the Dream as we Age



Unique Features



- ▶ Integration of person-centered and family-centered philosophies
- ▶ Peer support
- ▶ Inclusion of Peer Trainers
- ▶ Problem solving around family dynamics and family values
- ▶ Focus includes both current and potential community supports
- ▶ Guest presenters with content specific to state/local level

Letter of Intent



- ▶ Includes essential information about the individual with a disability's strengths, preferences, interests, support needs, and health.
- ▶ Identifies goals:
 - ▶ to expand friendships and supports;
 - ▶ make future living arrangements;
 - ▶ arrange for postsecondary education, work, or retirement; and
 - ▶ designate a successor caregiver.

The Future is Now Outcomes

- ▶ One year follow-up pre=post randomized design
- ▶ Increase in future planning activities, including writing letter of intent, preparing a special needs trust, and initiating planning for future living arrangements.
- ▶ Reduction in caregivers' burden and increase in the daily choice-making of individuals with IDD (Heller & Caldwell, 2006)



Transition The Future is Now Curriculum From In-Person to Virtual

- Conducted virtual train the trainer with sites in 8 states with the Arc (Owen et al., 2021)
- Virtual Future is Now using Zoom for real time interactive sessions.
- <https://ahs.uic.edu/disability-human-development/lifespan-health-community-living-and-intellectual-developmental-disabilities-research-and-training-programs/virtual-future-is-now/>
- <https://futureplanning.thearc.org/>



Example of Taking the Big Step

- ▶ Awareness of need to plan
- ▶ Overcoming barriers
- ▶ Getting the family together
- ▶ Figuring out elements needed
- ▶ Addressing self-determination of person with IDD
- ▶ Starting to develop an action plan

Katie's Family Future Planning Journey



Family Meetings



We quickly discovered that we all had very different assumptions about what the future would hold.

How to get the conversation started

- ▶ Starting the conversation is the hardest part
- ▶ Think about what you want to say and what you want to know
- ▶ Who should be part of the conversation?
- ▶ When is a good time to talk?
- ▶ Where Do You Feel Comfortable Bringing This Up?
- ▶ How to Break the Ice
- ▶ Be Patient and Realistic

Source: The Arc's Tips for Siblings: Getting the Future Planning Conversation Started: <https://thearc.org/resource/tips-for-siblings-getting-the-future-planning-conversation-started/>



Tips for Siblings: Getting the Future Planning Conversation Started



Your family needs to plan for how your sibling will live in the future, but starting the conversation can be very difficult. Here are some tips to prepare you to start talking with your family.

What do you want to say to your parents and sibling?
Think about what you want to tell your family about the importance of planning for the future. What role do you foresee playing in your sibling's life in the future? What other obligations do you have in

Making Decisions as a Family





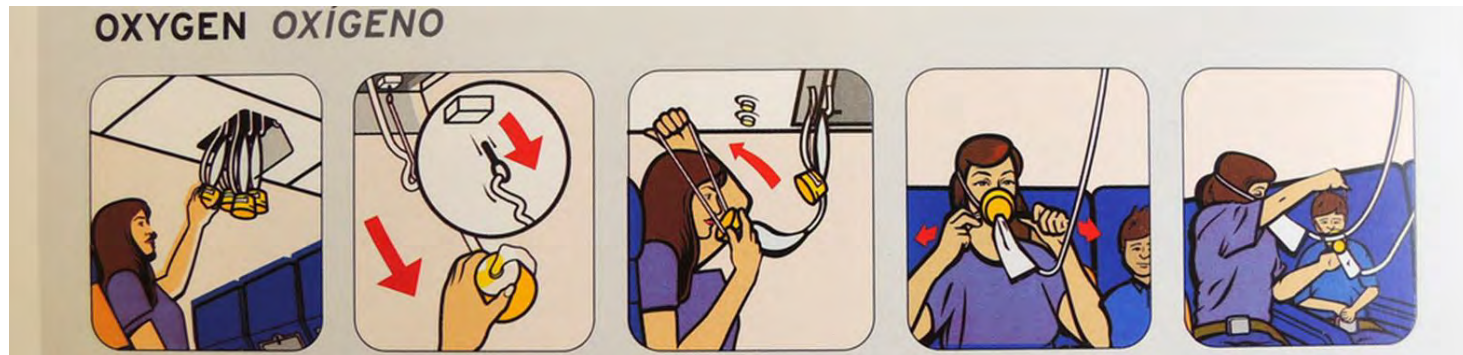
Family Dynamics



Peace of Mind is an outcome of
future planning

Taking Care of Yourself

- ▶ Self-care can be beneficial to you as well as everyone around you.
- ▶ *What can you do to take care of yourself?*
- ▶ *Make a list of what helps you feel rejuvenated in your life and what is important for you to take time to do for yourself.*
- ▶ Planning for the future can be a form of self-care.



Next Sessions

- ▶ Webinar #2: June 8th 12-1pm CT:
Nuts and Bolts of Family Future Planning
- ▶ Webinar #3: June 15 12-1pm CT:
Engaging with Aging in the Future Planning Process

Contact Information

- ▶ Dr. Tamar Heller and Dr. Katie Arnold
theller@uic.edu, kkeiling@uic.edu

Funded by National Institute on Disability, Independent Living and Rehabilitation Research, Administration on Community Living, grant # 90IFRE0051 to the University of Illinois Chicago.

