

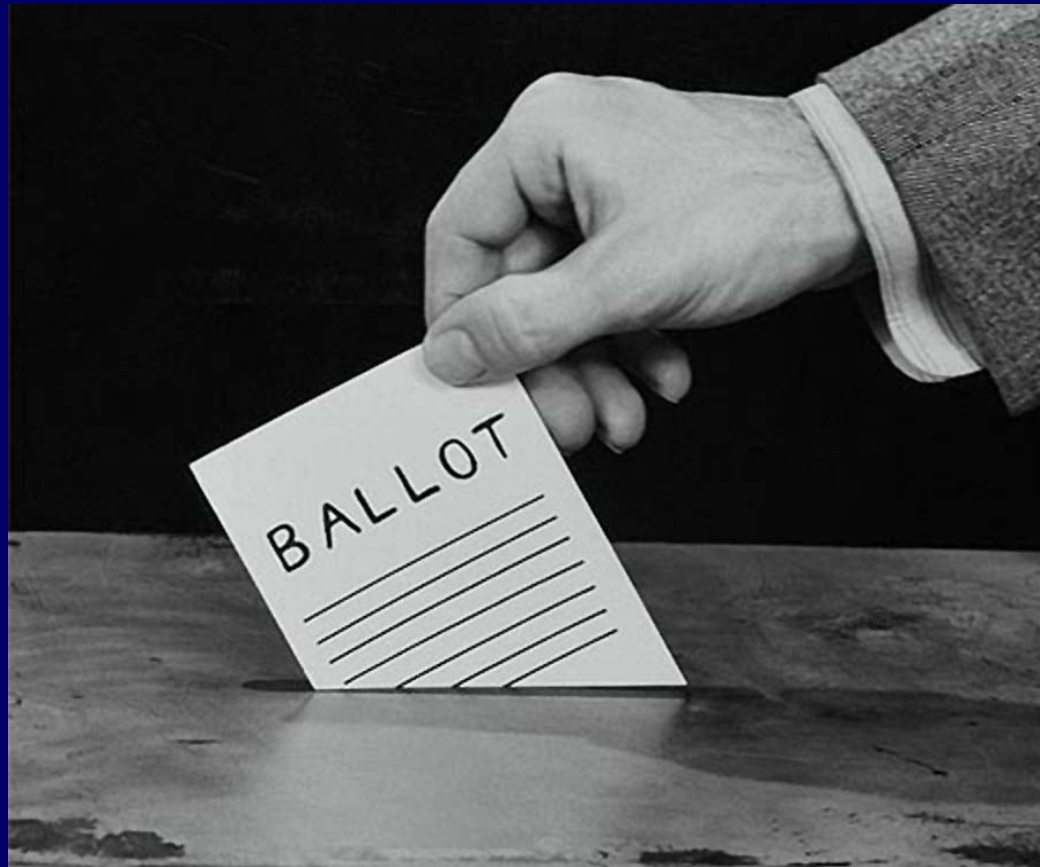
# **Future Care Planning and Consumer Directed Services:**

## **Integrating Perspectives of Aging Parents, Siblings, Persons with Disabilities and Service Providers**



Lynne Tomasa, PhD, Tamar Heller, PhD and Katie Arnold, MS

# Happy Election Day



# Aging & Transitions Project: Future Care Planning

Today's Focus:

- Caregiver Study (Interviews)
- Roadmap for Family Caregivers
- Future Planning Web-Module



# Guiding Research Questions

- What types of plans do aging caregivers make?
- How do aging caregivers and their families start to plan?
- What factors hinder or promote the process of future care planning ?

# Caregiver Study

## Participants

- 23 females and 7 males
- Ages 48 – 84
- 24 were parents; 3 were siblings; 2 were grandparents; 1 unknown
- Caregiving role: 9 – 56 years

# Persons with a Disability

- 12 females and 18 males
- Ages 14 – 66
- 28 involved in state funded program
- 18 lived at home



# Primary Findings

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- Planning is an evolving process
- Start process earlier
- Different aspects and tasks
- Cohort differences & influences
- Complicated emotions and behaviors

# Outcome: Caregiver Roadmap

- Designed as workbook/roadmap
- Address one's personal "journey"
- Five Sections
- Includes checklists, self reflection questions, information, resources



# Future Care Planning: A Roadmap for Family Caregivers

Sonoran University Center of Excellence in Developmental Disabilities  
Education, Research, and Service (UCEDD)  
University of Arizona, Department of Family and Community Medicine



Cover art by Tina Collazo from ArtWorks Day Program.

Date of 1<sup>st</sup> Plan: \_\_\_\_\_

Dates Revised: \_\_\_\_\_

First Edition (021210)

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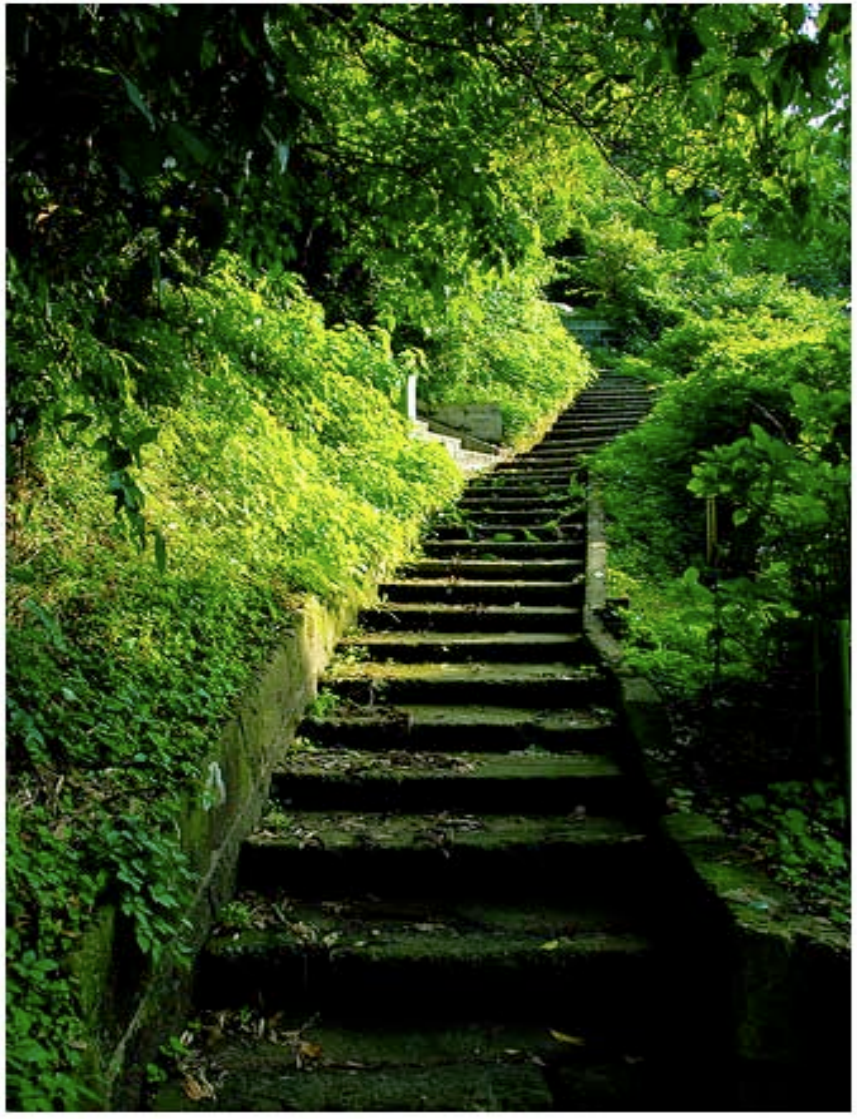
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It's time to  
begin your  
journey

# Additional Outcomes

- Caregiver support groups
- "Extreme Parent" group led by parent
- Caregiver Roadmap as guide and peer support
- Re-designed roadmap which led to web module!

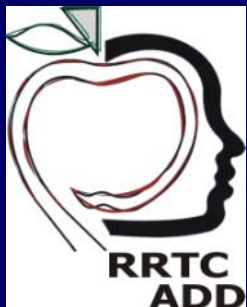
# Aging and Transitions Project

- [http://sonoranucedd.fcm.arizona.edu/projects/aging\\_and\\_transitions\\_project](http://sonoranucedd.fcm.arizona.edu/projects/aging_and_transitions_project)

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# Siblings: The Next Generation

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**Department of Disability and Human Development  
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**Website: [www.rrtcadd.org](http://www.rrtcadd.org)**

# Siblings: The Next Generation

- Siblings have longest lasting relationship and impact each other throughout lifespan
- Limited research on siblings of people with DD and findings show mixture of positive and negative outcomes
- Siblings are in a natural position to become the next generation of caregivers

# Importance



- Aging parents
- Increased caregiving role of siblings
- Sibling support needs will increase
- Addressing needs will lead to better outcomes for families
- Support needs of adult siblings have NOT been examined



# Research Question

What are the concerns and support needs of adult siblings who have a brother or sister with developmental disabilities?



# Methods



- Supporting Siblings Survey developed by Tamar Heller and John Kramer
- Recruitment: Online through SibNet (n=108) and statewide sibling conference (n=31)
- Sample: 139 adults sibling age 18-62 years, 92% female, 87% Caucasian

# Analysis

- Grounded theory approach
- Qualitative content analysis
  - Overarching themes
  - Core variables
- Intercoding and Member Checking



# Findings

- A voice for siblings
  - Value siblings
  - Advocacy
  - SibNet and SLN
- Caring for the caregiver
  - Multiple caregiving roles
  - Include siblings in family support
- Knowledge is Power
  - Future planning—Future is Now
  - SLN policy whitepaper



# Policy Implications

- SLN and SABE partnership
- DD Act and DD Councils
- Long-term care policy

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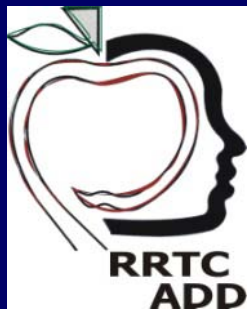
# Consumer-Directed Support: Impact of Hiring Practice on Families of Adults with Intellectual and Developmental Disabilities

T. Heller, L. van Heumen, K. Caldwell, E. McBride, K. Arnold, A. Factor

AUCD annual meeting and conference  
Crystal City, VA  
Nov 2<sup>nd</sup>, 2010

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# Consumer Directed Services

- Most adults with I/DD in US live with families
- Growth of funding for those living at home or independently
- Growing movement of consumer directed supports
- Over 48% of family caregivers make less than \$25,000 and 62% over age 66 (National Core Indicators)
- Most states allow families to be paid, including parents

# Aim

- Examine differential experiences and outcomes for family caregivers and adults with I/DD who receive services based on type of personal assistant (PA) hired
  - Family, Friends/Neighbors, Agency, and Non-Agency Staff



# Hypotheses

- **H1:** Hiring family and friends will be associated with higher satisfaction, lower turnover of PAs, higher caregiving satisfaction and lower burden for primary caregivers.
- **H2:** Hiring a parent will be associated with *lower choice-making* by the person with I/DD than hiring other relatives, friends, or others.

# Methodology

- Survey of families receiving Home Based Support Services (adult Medicaid waiver)
  - National Core Indicators Family Survey
  - Additional survey of family experience with personal assistance services
- Interviews with adults with I/DD

# Measures-Family Caregiver

- Caregiver Self-efficacy in managing and hiring PAs
- Satisfaction with PA
- Caregiving Satisfaction
- Caregiving Burden
- Community Participation of adult with I/DD
- Daily Choice Making of adults with I/DD

# Study Participants

- N=446 families (25% response rate) in the Illinois Adult Home Based Support Services Program
- 254 caregivers hired PAs other than themselves.

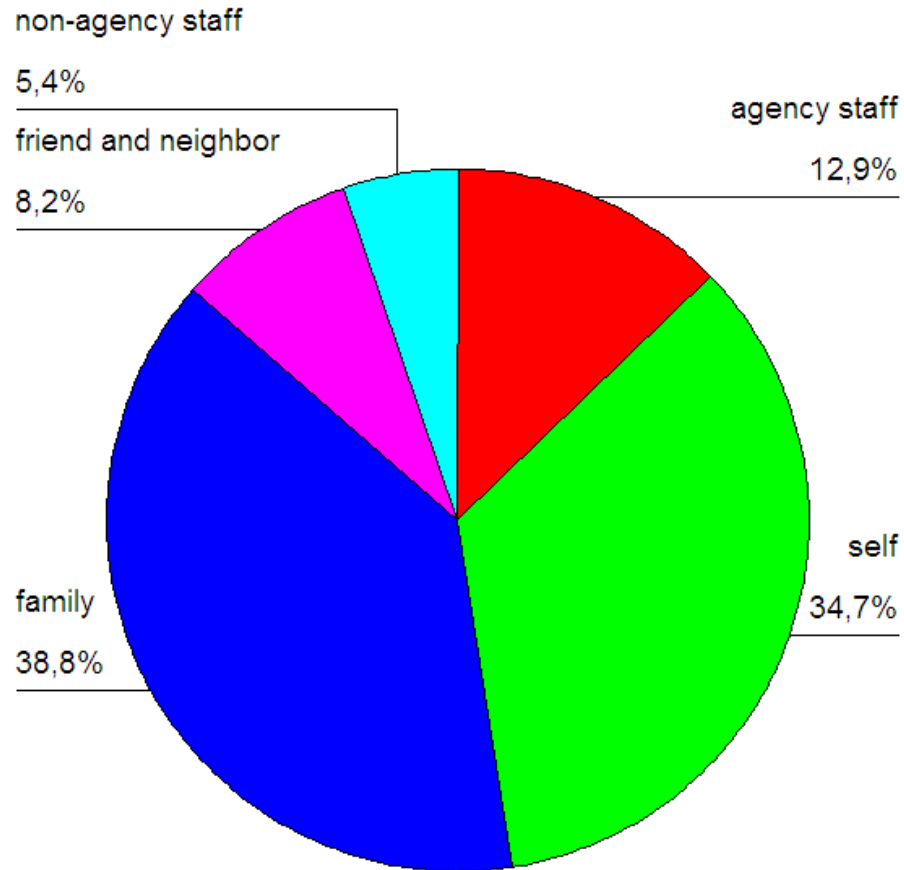
# Demographics of Caregivers (N=521)

- Mean age: 57.21 years, range from 21-85 years
- 81.4% female
- 60% married, 57.7% employed
- Relationship to person with IDD:
  - Parent (87.8%), sibling (8%), other (4.2%)

# Characteristics of Person with I/DD

- Mean Age: 30.80 years, range from 18-82 years
- 61% males, 39% females
- 71.4% White, 15% Black, 7.4% Hispanic
- Level of ID: mild (13.3%), moderate (32.6%), severe (21.7%), profound (13.3%), no ID (4.8%)
- Primary diagnosis: autism (18.8%), cerebral palsy (23.6%), Down syndrome (14.2%), brain injury (5.8%)
- Health condition: mental illness (8.6%), seizure disorder (28.4%), visual or hearing impairment (17.3%), physical disability (25.1%), communication disorder (18.6%)

# Who did they hire?



# Demographic Differences

- Type PA hired differed by caregiver gender and income.
  - Female more likely to hire themselves (39% versus 18%)
  - Analyses controlled for gender of caregiver



# Description of PA Services

Excluding self as PA:

- Average hours weekly = 25.9
- Average number of PAs in past year = 1.96
- Number of PAs who stopped working = .37
- Number of years with same PA = 5.24

# Benefits of Program

- Main benefits to family noted:
  - Increased employment
  - Take better care of health
  - Socialize more
  - Better afford health insurance
- Main benefits to person with I/DD:
  - Live at home longer
  - More recreational activities
  - More community activities
  - Able to buy assistive technology equipment
  - More employment

# Results (excluding self)

- Satisfaction with PA
  - Highest level of satisfaction with family members
  - Followed by friends/neighbors
  - Lowest for agency staff and non-agency staff
- PA risks were seldom experienced
  - Mostly for agency staff and non-agency staff
- Self-efficacy with hiring and managing PA
  - Highest with non-agency staff
  - Followed by friends/neighbors and family
  - Lowest for agency staff

# Outcomes for People with I/DD

- No significant differences in choice-making or community participation based on type PA
- When exclude self as PA choice-making highest with non-agency staff and friends and neighbors, followed by family and agency staff.
- Need to get perspective of people with I/DD
- Next phase of study includes interviews with people with I/DD

# Future Research

- Training Intervention to help persons with I/DD and families better direct their supports with following goals:
  - Involvement of both the family and person with I/DD in planning and setting goals
  - Higher satisfaction with PA services
  - Greater community participation and choice making of person with I/DD
  - Attainment of goals set by persons with I/DD and their families

# Future is Now Curriculum

## **The Future is Now : A Future Planning Curriculum for Families and Adults with Developmental Disabilities**



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# Directing Own Supports

- Find, Choose, and Keep Great DSPs
  - toolkits two versions (family and individual)
  - provides strategies to help people find, choose and keep high quality Direct Support Professionals.

