

Family Caregiving and Future Planning: "The Future is Now

Rehabilitation for Wisconsin

It's a Wonderful Life! Aging with Developmental Disabilities

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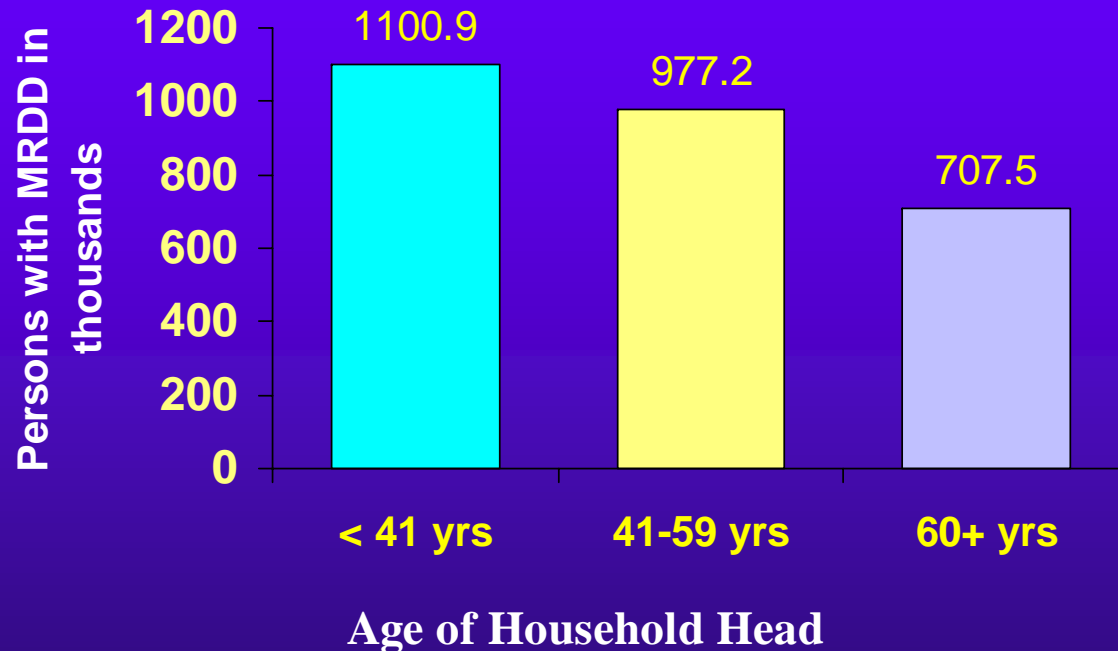
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"As I see it, you bring a child into the world--you're responsible for him.

You have to set up care for as long as possible."

Emerging Challenges: Demographic Wildcards



Aging Household Heads:

- approximately 25% of the home-based live in homes headed by elderly parents or other relatives
- 13,046 aging caregivers in Wisconsin

Families are the Primary Providers of Care

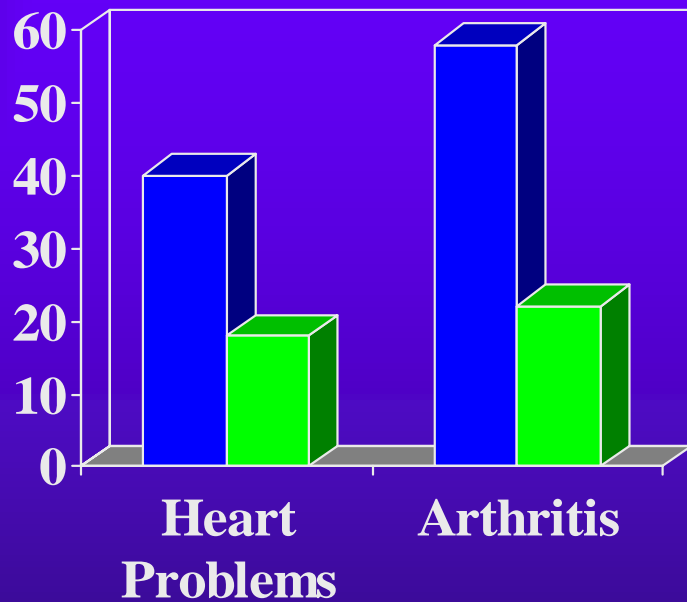
- Longer period caregiving
- Traditional parental roles persist into adulthood
- Fewer family members to provide care
- Families provide most of social-recreational support
- Many are not known to the disability service system
- Adult child with disabilities provides support to parents or others in the family

Impact on Caregivers

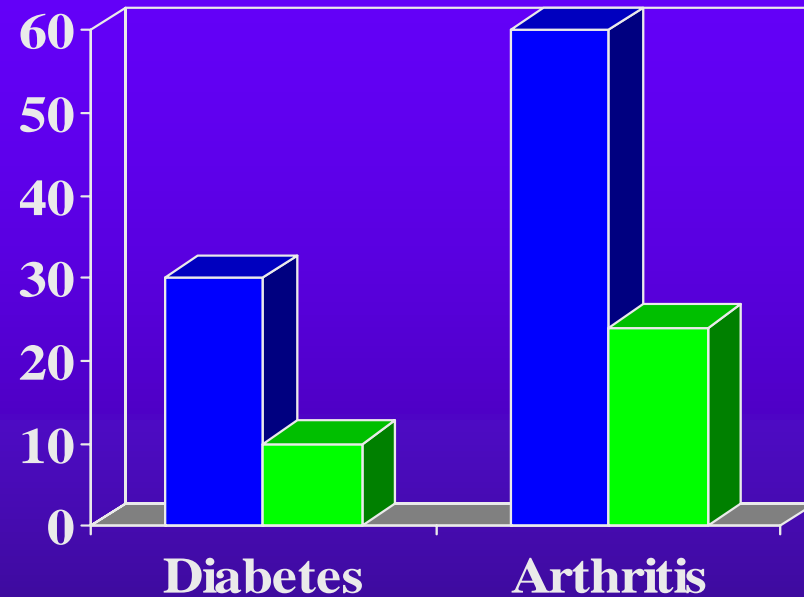
- Need to deal with aging of self and adult child
- Impacts on Families
 - Maternal employment
 - Caregiving burden and satisfaction
 - Physical and mental health of parents
 - Less time with friends

Health of Low-Income and Minority Caregivers

Older Latina Caregivers



Older Black Caregivers



■ Older Latina or Black Caregivers

■ Peers

After Parents Die

- Need for services will increase
- More likely experience change in residence and work
- Better adjustment if made future plans
- Grief reactions often not dealt with adequately
- Siblings become primary caregivers

Sibling Involvement

- Socialization experiences
- Closeness in the past
- Proximity
- Gender
- Severity of behavioral problems
- Current support provided (socio-emotional)
- Current involvement in dd related activities

Need to Plan for Future Needs

- Many families do not make plans and are unaware of legal and financial options
- Planning is related to resources, ways of coping, and options in the community
- Lack of collaboration between aging and disability service system
- Many families have avoided contact with formal disability services

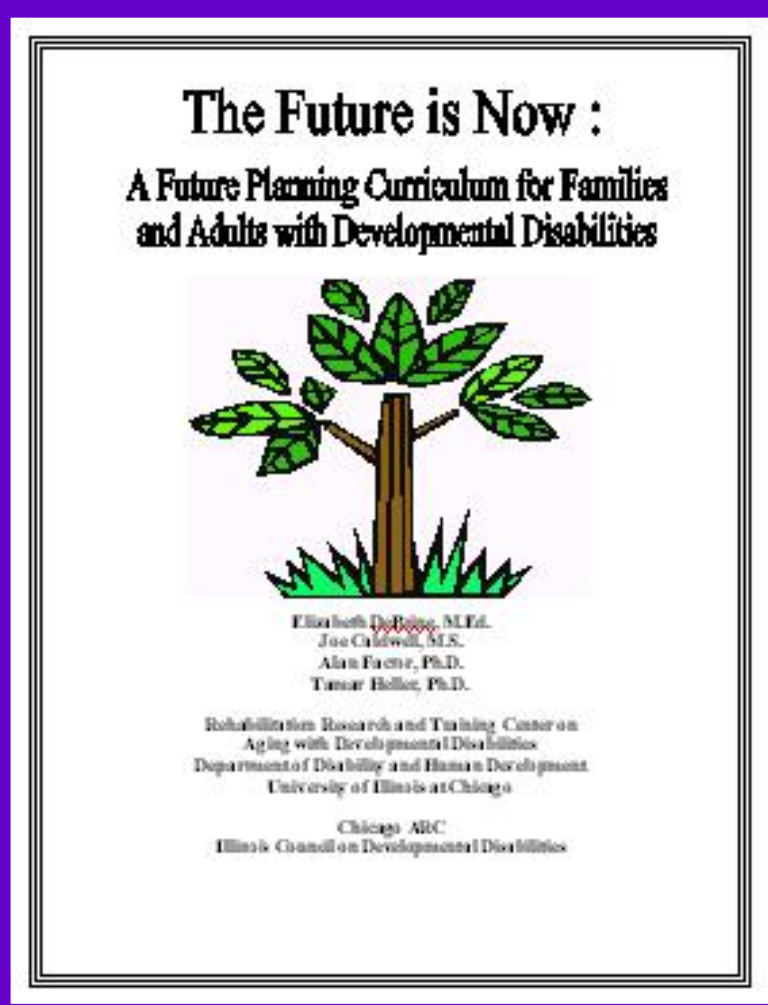
Barriers to Planning

- Anxiety of facing own mortality
- Lack of information on financial issues and guardianship
- Lack of access to services
- Mistrust of professionals
- Age-related needs
- Daily demands of caregivers and procrastination

Future Planning Approaches

- Family Future Planning Project in Rhode Island
- Planned Lifetime Advocacy Network (PLAN) in British
- Family-to-Family Project in Massachusetts
- RRTC on Aging with Developmental Disabilities Family Future Planning Project

The Future is Now Curriculum



Unique Features

1. Peer support
 - Families and individuals with ID share information/ experiences and support each other
2. Inclusion of Individuals with ID
 - Adapted RRTCADD Person-Centered Planning for Later Life
3. Evaluation of Outcomes

Training in Choice-Making and Self-Determination

- Person-Centered Planning for Later Life: A Curriculum for Adults with Mental Retardation (Sutton, Heller, Sterns, Factor, & Miklos, 1993)
- Making Choices as We Age : A Peer Training Program (Heller, Preston, Nelis, Brown, & Pederson, 1996)
- Voices that Count (Pederson & Chaikins, 1993)
- Leadership Today (Pederson & Nelis, 1998)

Person-Centered Planning Curriculum

- 17 weekly sessions
 - Understanding aging
 - Making choices
 - Living healthy
 - Using free time
 - Working and retirement
 - Making friends
 - Making a home
 - Setting goals and action plans

Person-Centered Planning: Lessons Learned

- Benefits noted in US, Germany, and the Netherlands
- Learned about later life options
- Increased choice-making
- Many goals attained through support from staff and families

Goal Attainment

6 Month Follow-up

- Obstacles
 - Lack of staff follow-up (31%)
 - Lack of transportation (31%)
- Supports
 - Staff follow-up (50%)
 - Family follow-up (15%)
 - Transportation arranged (8%)
 - Change in agency policy (8%)

Training, Support, and Advocacy

- Setting up a planning group including aging and DD agencies, families, people with disabilities
- Training of peer trainers
- Training in legal financial planning
- Monthly training sessions
- Follow-up phone calls
- Resource manuals
- Website support

Curriculum Overview

- 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
- Development of Letter of Intent
- Legal/Financial Planning Session (full day)

Five Workshops

1. The Big Step

- Build group cohesiveness and momentum
- Identify barriers to planning
- Name dream and nightmare for the future
- Document family history

Five Workshops (2)

2. Building Relationships & Skills

- Identify circle of support
- Develop strategies to strengthen relationships and community involvement

3. Housing

- Gain additional information on residential options
- Document future preferences and take action towards

Five Workshops (3)

4. Work, Retirement, & Leisure
 - Gain information on employment and recreational options
 - Document preferences and desires
5. Who Will Be the Keeper of the Dream?
 - Identify future caregivers/supports and safeguards for the future.
 - Develop at least one family future planning goal for the next 6 months.

Workshops for Individuals with DD



Curriculum for Individuals with DD

WHAT CHOICES DO YOU MAKE

(List Choices You Make in the Boxes)

WHAT TO EAT FOR A MEAL OR SNACK



WHAT TO WEAR



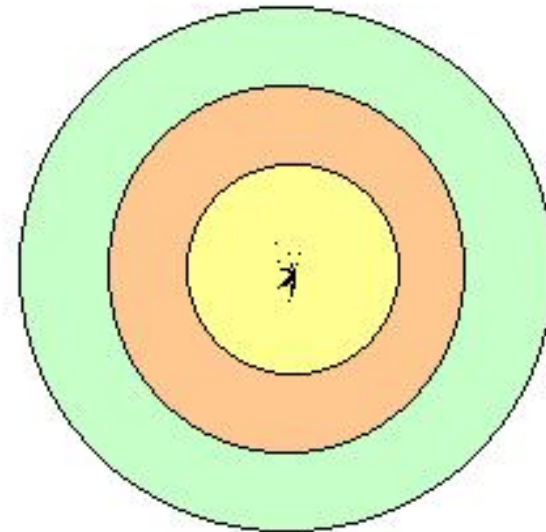
WHAT TV SHOW TO WATCH



HOW TO SPEND YOUR MONEY



Circle of Support



Pre-test: Individuals with Disabilities

- Individuals with disabilities (n=24)
 - 64% could not name any of their rights
 - 70% could not name 2 different places to live
 - Only 50% said you should “speak up about what you want” during a meeting to plan for the future

Workshop: Family Caregivers

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



Goals of Future Planning

- Examples of 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 successor guardian
 - Look into housing options
 - Support son to attend People First meetings
 - Support son with interest in dating

The Future is Now Evaluation

- Pre-test & 6-month follow up surveys with family caregivers
- Pre-test & 6-month follow up interviews with individuals with DD
- Control group of family caregivers who attended one day legal/financial session only

Summary of Key Outcomes for Participants

- Special Needs Trust
 - 24% who did not have have a special needs trust developed one
- Residential Planning Action
 - 64% who had not taken action on planning for residential needs did so
- Letter of Intent
 - 78% developed a Letter of Intent
- Caregiving Burden
 - Compared with control group, caregiving burden significantly decreased over time

Summary of Key Outcomes

- Daily Choice Making of Individuals with DD
 - Caregivers in the intervention reported their relatives with disabilities making significantly more daily choices over time.
- Leisure Activities of Individuals with DD
 - Individuals with disabilities reported doing more leisure activities and less unmet needs.

Outcomes:

Quotes from Families

- “We learned what other caregivers are doing.”
- “My daughter benefited from walking through the process. She knows what will happen if something should happen to mom and dad.”
- “We are sharing information with parents of younger children to encourage them to think about the future –Time slips by so quickly.”
- “I am discussing plans with other relatives.”
- “ I learned that if I don't do it no one else will.”
- “I should have done this 15 years ago !”

Systemic Outcomes

- Group of individuals with DD developed People First Chapter
- Families led additional workshops
- Agency adopted letter of intent
- Collaboration with Illinois Department on Aging

Outcome: Resource Guide

Future Planning Resource Guide



For Families and Adults with Developmental Disabilities in Illinois

Rehabilitation Research and Training Center
on Aging with Developmental Disabilities

CARC

Illinois Council on Developmental Disabilities

Recommendations

- Peer model seems to be one effective way to support families in future planning
- Systemic Issues
- Inclusion of siblings and other family
- Agencies can incorporate curriculum/letter of intent to facilitate family and agency planning

Limitation

- Planning is a long process
- Peer trainers vary in attitudes and experience
- Time intensity
- Takes commitment of agencies