

Supporting Persons with Disabilities, Families, and Service Providers During Later Life Transitions and Future Planning: Role of Social Workers

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Objectives

Review:

- What We Know and Experience
- Research Studies: 2008 & 2016
- Preliminary Themes and Results
- Suggestions from Service Professionals and Family Caregivers
- Professional Role/Social Work



Literature

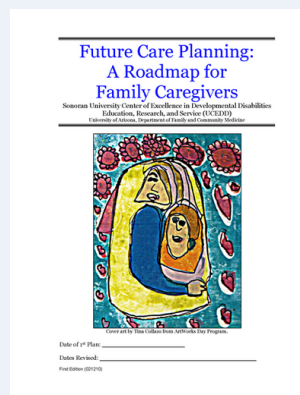
- Assessing families' service needs
- Effects of informal and formal resources on burden and placement
- Developing later-life-planning programs for adults with intellectual disabilities
- Caregiver Appraisal
- Giving families tools: peer support curriculum
- Siblings' role in future care and planning



Two Research Studies:

2007 – 2008

- Interviews with 25 family caregivers
- Analysis: Themes
- Outcome: *Future Care Planning: A Roadmap for Family Caregivers.*



2015 – 2016 Follow-Up Study

2015 – 2016

- Interviews with individuals with IDD & family caregivers
- Follow-up with 5 CGs from first 2007-2008 study
 - Completed 30/40 Family Caregivers (FCG)
 - Completed 13/20 persons with IDD
- Online questionnaire for service providers (N=47) and CGs (N=96)



Study Objectives: 2015-2016

- Survey family caregivers (FCG) and service providers (SP) about their experiences and roles in supporting individuals with disabilities and each other during future planning and transitions of care.
- Interview both individuals with disabilities and family caregivers about
 - Wishes and needs during the planning process
 - Accomplishments and next steps
 - What works and what does not
 - Experiences and emotions



Demographics: Service Providers

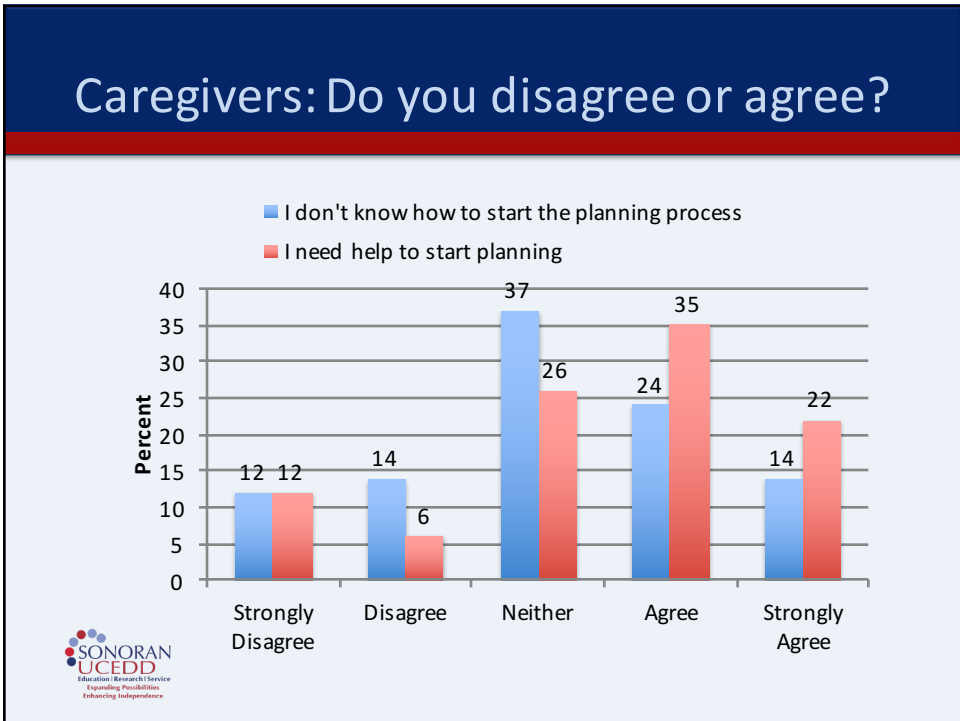
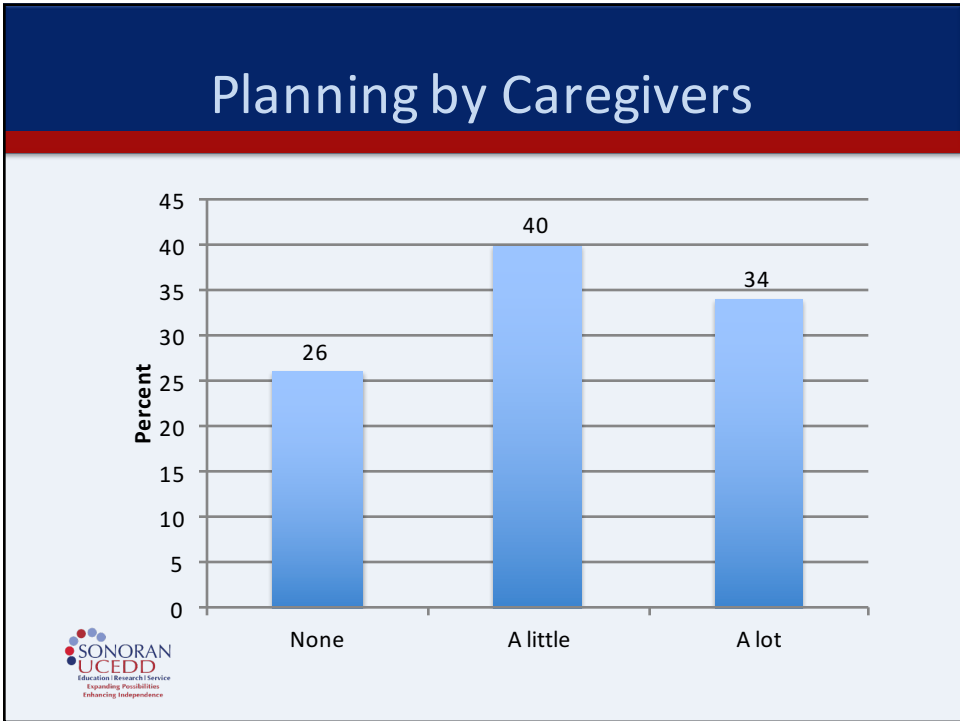
- Experience: 62% < 9 yrs.; 38% > 10 years
- Roles: Direct service 16%; Support coordinator; 22%, other: 62%
- Community Served: 26% with persons 60 years and older



Demographics: Family CGs (N=95)

- 84% were primary caregiver
- 82% of person with disability had siblings
- 76% of persons with IDD lived with CG
- 11% had change in residence in past year
- 53% had full guardianship, 11% no legal role





Thoughts or emotions FCGs shared with service providers N=45

Thought or Emotion	Count
Negative experience with service providers	34
Fear	33
Mistrust of the service system	31
Denial	27
Positive experience with service providers	25
Need for control	23
Hopelessness	22
Sense of loss	20
Ambiguity	16
Other	6



Thoughts or emotions caregivers have experienced N=86

Thought or Emotion	Count
Negative experience with service providers	50
Mistrust of the service system	50
Fear	45
Sense of loss	33
Hopelessness	32
Positive experience with service providers	29
Need for control	28
Ambiguity	28
Denial	22
Other	20

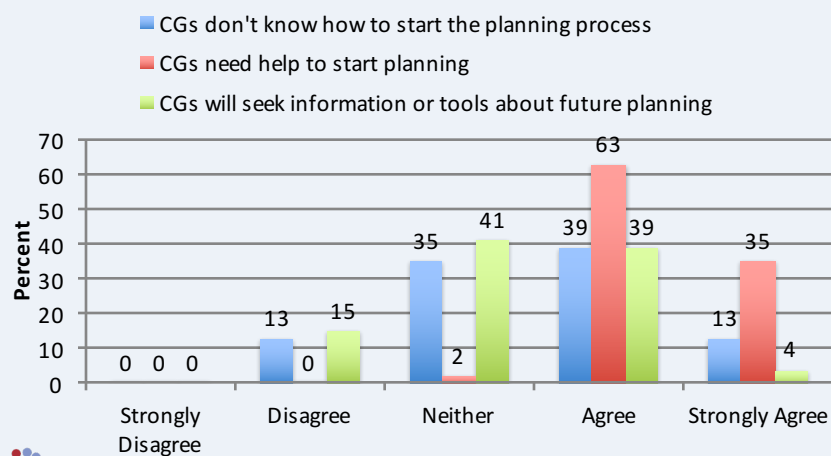


Triggers that made CGS start to think about future planning N=86

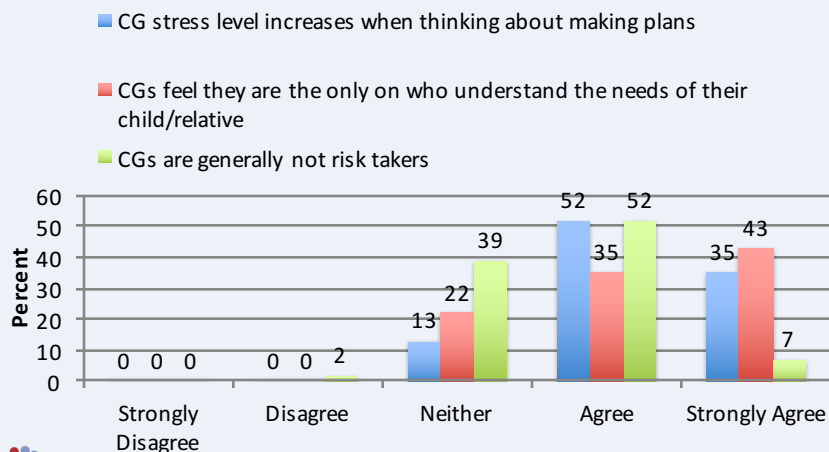
Triggers	Count
Age of caregiver	43
Changes in caregiver's health	27
Feeling exhausted	20
Behavioral changes in child/relative	19
Changes in child/relative's health	13
Child/relative communicated desire to move out	12
Another person I/we know made plans	9
Siblings offered to get more involved in providing care/support	5
Other	33



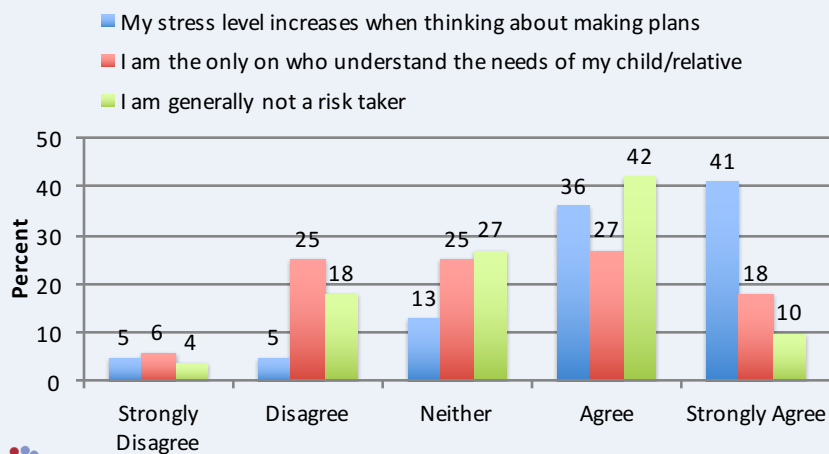
Future Planning: Service Providers



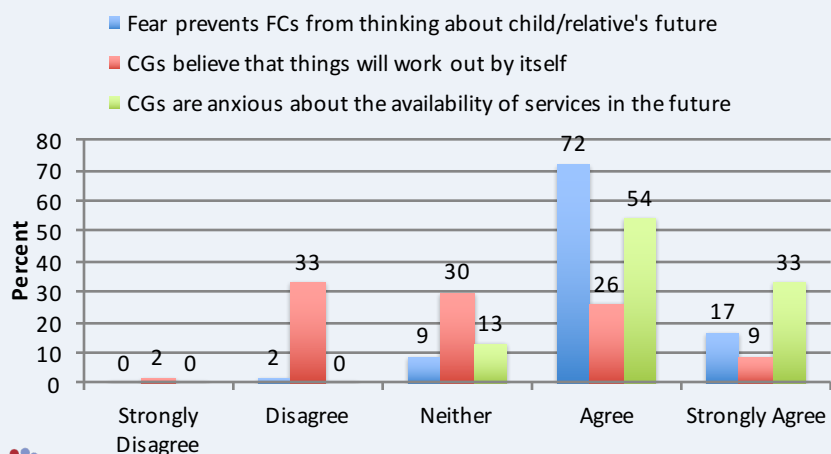
Future Planning: Service Provider



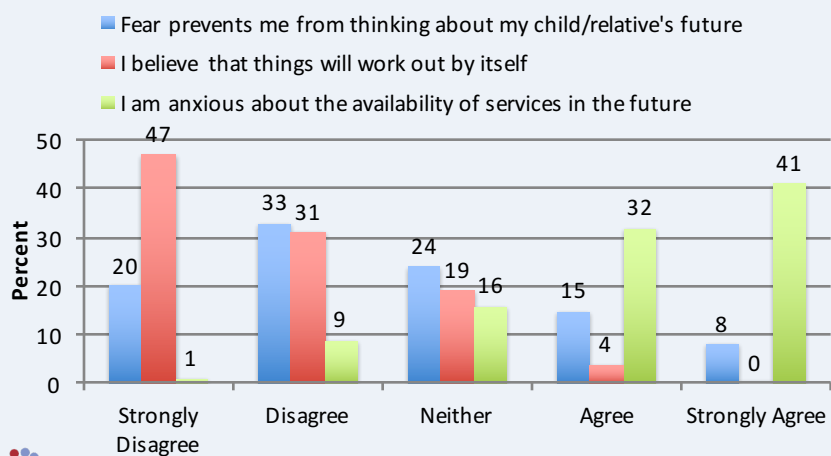
Future Planning: Caregiver



Future Planning: Service Provider

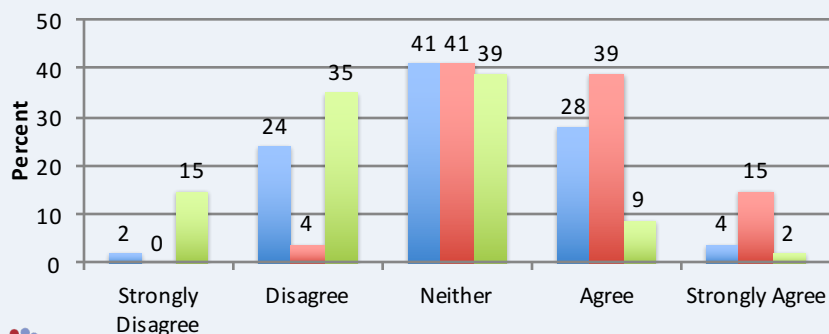


Future Planning: Caregiver



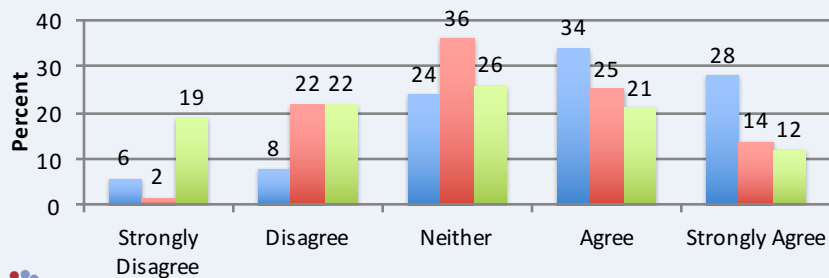
Future Planning: Service Provider

- CGs are ready to support their child/relative's desire for more independence
- The person with a disability is an important source of companionship
- CGs are willing to let go of their caregiving role



Future Planning: Caregiver

- I am ready to support my child/relative's desire for more independence
- My child or relative with a disability is an important source of companionship
- I am willing to let go of their caregiving role



Meet Dirk, Dad, Sister (2008 & 2016)



Themes

2007-2008

- Triggers
- Barriers and challenges
- Successes
- Systems
- Health and care delivery
- **Emotional responses of caregivers**

2016 (Preliminary)

- Experiences
- Emotions
- Other Persons involved
- Systems
- Wishes and goals
- Support needs
- Suggestions & lessons



Thematic Highlights

- It is a process that evolves and changes
- Evokes a broad range of intense emotions
- Planning must start early
- Families want information
- Decisions about residential options are very difficult



Highlights

- One-on-one assistance is needed
- Families are very frustrated and need help to navigate through systems
- Centralized information is helpful
- We are asking caregivers and individuals to go out of their “comfort zone” – professionals need to do that too



Helpful Strategies: from SPs

- Provide parents with success stories
- Include individual's vision
- Understand that lifelong conversations are hard for families
- Be honest
- Focus on quality of life
- Value the role of the caregiver



Helpful Strategies: from Caregivers

- Be honest, gentle, straightforward
- Show/tell CG and individual with IDD about choices that have been made by people he/she knows
- Have a check list/to-do list
- Provide concrete information
- Ask opinions of the person with a disability



What is your role?

- Advocate
- Community builder
- Coach
- Educator
- Facilitator
- Fact finder
- Informationist
- Mediator



Professional Role

Build communication skills and strategies

- Be honest and gentle
- Be direct and clear
- Provide examples
- Engage and welcome input from others
- Stay neutral
- Utilize simple words and phrases
- **Be present and curious**



Professional Role

- Assist with goal setting (dreams, hopes)
- Identify unfinished business
 - Personal, family, spiritual
- Encourage continued networking
 - New relationships and opportunities
- Identify comfort level with risk taking



Professional Role

- Value the caregiver role
- Acknowledge the difficulties and rewards
- Allow caregivers to grieve
- Give permission to have negative thoughts or feelings
- Acknowledge fears and anxieties



Summary Points

- Transition/future planning can be hard
- Pay attention to caregiver emotions
- People need information and support
- Provide avenues for expression and engagement
- Address grief and loss
- Minimize professional burnout and mental/emotional saturation



Questions and Suggestions

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