Aging caregivers identified that future planning is an ongoing process that is never static. During this process there is no single factor that facilitates or triggers the discussion or completion of a future plan. Among the important components of a future plan, our qualitative analyses explored three key factors.

**Emotional responses** play a role in a person’s ability or willingness to complete a future plan. Interventions and education must be continuous and ongoing for success. Peer and family support are important throughout the planning process; even families who have the knowledge and resources to develop a formal plan experience ambivalence about doing so.

**Implications/Next Steps:** It is important to understand the emotional responses triggered when future planning is discussed and implemented. A coordinated community effort is necessary.

### Background

Future planning involves decisions regarding living arrangements; maintaining social and family contacts; continued integration in the community; legal and financial issues; and quality of life. Research on successful interventions and opportunities has been reported.

**Objective**

- Identify future planning needs of older caregivers in AZ
- Explore what triggers older caregivers to make formal plans
- Explore issues/barriers caregivers face regarding future planning

**Methods**

- Recruited caregivers over age 55 across AZ
- Through statewide disability agencies & community groups
- Conducted 1 to 2 hour semi-structured interviews
- Areas of focus: 1) current caregiving situation, 2) health of caregiver and individual with DD, 3) concerns about future plan
- Administration of demographic questionnaire
- Transcripts read independently by 2 investigators
- Open coding identified emerging themes
- Qualitative software used: ATLAS.ti 5.0

**Demographics**

- **CAREGIVERS (11 transcriptions)**
  - Age: 47-75 years old
  - Gender: 8 females, 3 males
  - Length of caregiving: 9-51 years
  - Reported Health: Good to Excellent
  - Other: Educated, Medium to High Income

### Discussion

- The data supports prior findings about future planning barriers.
- Emotional responses (fear, ambivalence, dependence, disappointment, frustration) play a key role in one’s ability to move ahead in future planning. Interventions must also include a component that addresses these issues. These emotions can come in swings and support programs and education must accommodate these changes.
- Caregivers often feel disconnected and isolated. Peer, community, and family support must be available and ongoing.
- Communities need to develop a mechanism/strategy to sustain the level of support through all life stages.

**Themes – Preliminary Data**

**Planning as an ongoing process: timing and triggers**

- "I don’t know… but I don’t feel 30 instead of 73. …when I feel like I’m not able to do well, we’ll just bring in help."
- "I think we were feeling very old… kinda when life hits you that parents die, we could die."
- "It’s very important to know that there are no easy answers to any questions. There is no time frame of people’s process through the journey"
- "Just because the body doesn’t work doesn’t mean that there is an emotional level of a young man who says...let me grow up and do something else."

**Emotional responses**

- Desperation - "I need a back up – I need somebody that can be trained so that when I’m not here…I’m talking about the transition, if something happened to me…literally all hell would break loose."
- Dependence - "I won’t be happy till he joins me in heaven.”  "You know, he was my life for years."
- Ambivalence - "Never talked too much about it but they would take care of her"
- Fear - "Well, you’ve taken care of the person since they’ve been small and you thought the system did everything …you finally have to sit there and sort of firm up that you can’t last forever and you have to make sure that whoever can continue giving that person all of your life."

**Maintaining connections**

- Advocacy - "I’m running a little bit scared… and it’s crossed my mind in the middle of the night – who will poke their head in on him?"
- Guidance - "It would be really great if they were educating those of us above 50 as to what is out there… If …could bring us together and say okay this is what you need to be thinking about now."
- Support - "Nobody teaches any of this – I don’t know if there’s any place to go. Where people talk about it, discuss it. What I have learned has not been through any system here – it’s because of the work I do."
- Philosophy of Care - "I have tried to make his life as normal as possible, so I would want them to understand that I want his appearance to look good. Even though he may not understand, the outside world understands. I would like him to go out into the community to do things, to be part of the world, to have a joy in life and to be well taken care of."