

Sonoran UCEDD

University Center of Excellence in Developmental Disabilities Education, Research and Service

Aging and Transitions Project Technical Report and White Paper

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EXECUTIVE SUMMARY

The University of Arizona's Sonoran UCEDD (University Center for Excellence in Developmental Disability Education, Research, and Service) was established in 2006. One of its goals is to promote effective transitions for caregivers and persons with developmental disabilities (DD) as they age. As part of this goal, the *Older Caregivers and Transitions Study* (OCAT) was implemented in 2007 – 2008 to explore the barriers to effective late-life transitions for older caregivers who were providing direct care and support for a family member with DD. This study is important because of the growing number of older adults as well as the increasing life expectancy for persons with a developmental disability. The changing demographics impact the demand for and types of individual, community, and in-home supports necessary for caregivers and persons with DD.

Older caregivers for the OCAT study were recruited statewide and ranged in age from 47 to 84 years old. The caregivers provided a combination of direct care, support, and monitoring in an informal or unpaid capacity for a family member with DD. Caregivers participated in individual interviews or focus groups that were tape-recorded and transcribed. Family members receiving care and support ranged from 14 to 66 years of age and lived either with the caregiver(s) or in residential settings in the community.

The results of the interviews and focus groups identified five major themes. The first theme, *future care planning: components, timing, and triggers for transitional planning*, emphasized that it was difficult for caregivers to identify the “right time” to make future care plans and that this process involved components that were triggered by different experiences. The second theme, *psychological and emotional responses of caregivers*, highlighted that caregivers experience a range of psychological emotions such as fear and frustration as they begin to consider and make future care plans for a family member with DD. The third, *concerns, challenges, and successes*, focused on maintaining the quality of life for the person with DD regardless of where that person lived and with whom. Also evident were concerns about the availability and training of staff who serve as formal or paid caregivers; the fear of abuse and neglect; and legal issues such as guardianship. There was ongoing problem solving by caregivers that led to successful transitions into the community. The fourth theme, *resources and systems of care*, brought out the degree to which caregivers utilized support from family and friends and the role these people played in the life of the person with DD. Despite the important and helpful role of DDD, ALTCS, and service providers, families continue to struggle with staff turnover and timely need for services. The fifth theme, *health and health care delivery*, identified the resilience of caregivers. It also identified concerns about specific health issues of the person with DD and the ability to access important health related services.

Caregivers' experiences were diverse and rich and the research team is grateful for the opportunity to share a part of their lives. Caregivers are a valuable resource and in order for them to continue their important role, statewide systems of care, service providers, and the Sonoran UCEDD must work collaboratively to share information and resources to address caregivers' concerns and needs. Recommendations are made on how to better support caregivers and address the concerns they raised in their interviews.

Part One

INTRODUCTION AND BACKGROUND

The Sonoran UCEDD

There are currently 67 University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) in every state and territory. UCEDDs were initially created in 1963 with the enactment of Public Law 88-164 to serve people with mental retardation but now serve as a resource for Americans with a wide range of disabilities. The Centers are currently authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402). The Administration on Developmental Disabilities (ADD), part of the Administration for Children and Families within the US Department of Health and Human Services is the core funding source for each UCEDD. The shared vision of the UCEDDs is to “foresees a nation in which all Americans, including Americans with disabilities, participate fully in their communities. Independence, productivity, and community inclusion are key components of this vision” (<http://www.aucd.org>). To accomplish this Centers are affiliated with major research universities and play key roles in shaping major disability initiatives and facilitating the flow of disability-related information between their communities and university.

In 2006, the University of Arizona’s Sonoran UCEDD became one of three new centers created nationally. It joins the company of the well-established Arizona UCEDD at Northern Arizona University’s Institute for Human Development. The Sonoran UCEDD is engaged in numerous projects: Aging and Transitions Project, Medical Home for Youth and Adults with DD, Health Education Project, Employment Project, Border Initiative and Conference, and the Southern Arizona Model Person Centered Planning Program (<http://sonoranucedd.fcm.arizona.edu/>). Developmental disabilities are defined as those occurring prior to age 22 that are life-long and involve multiple functional limitations, such as learning, walking or speaking.

Aging and Transitions Project (ATP)

One of the goals of the Sonoran UCEDD is to promote effective transitions for older caregivers and persons with developmental disabilities (DD). Transitions include planning for the future. Our study hoped to answer the following:

- What will happen to the person with DD as their caregiver/parent ages and is no longer able to take as active a role or any role in their daily activities and care?
- How do parents and families start to plan for that future as they begin to age?
- What may hinder or promote the process of making future care plans?

The future care planning by a caregiver(s) for a person with DD may involve siblings, parent(s), other relatives or extended family members, community service providers, and other interested persons. A future care plan is the term used to describe a written document or conversation involving the aspects of future life for the individual with DD once the caregiver reduces or

leaves their current role. These plans often involve financial planning through trusts, identifying alternative residential settings if the individual with DD is still living at home, identifying a future caregiver or guardian, and addressing the social as well as psychological needs of the caregiver and the person with a DD. In this project, the person with a developmental disability is also referred to as the “care recipient” though we are cognizant of the fact that in some families the individual with DD may assist with chores and other care for aging parents.

The Aging and Transitions Project (ATP) is a five-year project that includes several activities. The early activities involve data collection that will help with future program planning and advocacy for older caregivers and adults with developmental disabilities. The goals of the Aging and Transitions Project are to:

1. Describe and address barriers to effective late-life transitions for older caregivers of persons with developmental disabilities
2. Promote effective late-life transitions and planning for adults with developmental disabilities
3. Improve aging-related and end-of-life care for people with developmental disabilities

This white paper will address the **first** activity of Goal One of the Aging and Transitions Project. This activity involved a research project that recruited and interviewed older caregivers in order to learn about the issues they face when planning for the future care needs of their family member with a developmental disability. The Older Caregivers and Transitions Study (OCAT) is described below.

Importance of The Older Caregivers and Transitions Study (OCAT)

Profile of Older Americans Aged 65 and Older

The older population is growing significantly and living longer. Approximately one in eight Americans, or 12.4% of the population, is 65 years of age or older. The population of older Americans is projected to increase from 35 million in 2000 to 40 million in 2010 (15% increase) and will jump to 55 million in 2020. This is a 36% increase in 10 years. In 2030, nearly one in five Americans will be 65 and older. In 2004, the average life expectancy for persons reaching age 65 was an additional 20 years for females and 17.1 years for males. In 2006, there was a gender ratio of 114 women for every 100 men for persons who were 65 - 69 years old. This gender ratio increases to 213 women for every 100 men for persons 85 and over (Greenberg/AoA, 2007). In 2008, the 85+ population numbered 5.4 million and is projected to increase to 8.9 million in 2030 and to 19 million in 2050 (U.S. Census Bureau 8-14-08). Arizona was one of 10 states whose 65+ population increased by more than 20% between the ten-year period of 1996 – 2006, representing a 34.9% increase.

Older Persons with a Development Disability

Persons with a developmental disability are also living longer. This directly impacts the demand for and types of community and in-home supports needed for themselves as well as their caregivers. In order to estimate the impact of aging on the demand for DD services, Braddock et al. (2008) examined data on the prevalence of DD in our society, the changing demographics, and data pertaining to the out-of-home residential care system in the states. National estimates reported by Fujiura (1998) and Braddock et al. (1999, 2008, pg. 61) indicate that the majority (60%) of people with intellectual/developmental disabilities (I/DD) in the United States reside with family caregivers. Based on 2006 data, the number of persons with I/DD who received care by family caregivers (referred to as “informal” system of care) was five times the number served by the “formal” out-of-home residential care system. Updated estimates show that of the 60% that live with family, 25% live with caregivers aged 60 years and older; 35% live with caregivers between the ages of 41 and 59; and 40% live with caregivers aged 41 and under (Fujiura, 1998, Braddock, 2008).

State by state estimates of residential services for all persons with I/DD vary. For example, Braddock et al. (2008) reported that in 2006, approximately 6% of persons with I/DD in Arizona lived in nursing facilities, state institutions or intermediate care facilities with 7 or more persons. Out of the remaining 94%, the majority (88%) lived in group homes or foster care. Only 12% of the remaining 94% lived in supported living residential settings that included “housing in which individuals choose where and with whom they live; in which ownership is by someone other than the support provider (such as the individual, family, landlord, or a housing cooperative); and in which the individual has a personalized support plan.”

In order to estimate the size of the caregiver cohort who are 60 and older who provide care for a family member with I/DD, Braddock et al. (2008, pg. 61) examines states’ utilization of out-of-home placements and the number of caregivers over 60 years of age. These numbers vary greatly between states. For example, Braddock et al. (2008, pg. 62) estimates that in 2006, 15,923 persons with I/DD lived with a caregiver 60 years and older. In the United States, it is estimated that 716,212 persons with I/DD live with caregivers aged 60 years and older.

At some point, middle-aged and older caregivers, with input from persons with I/DD, will need to explore alternate out-of-home living arrangements. America’s aging population reflects the importance of taking a closer look at the needs of caregivers and how we can better support them as they design appropriate future care plans for their loved ones with a developmental disability. The research in the area of aging and caregiving is briefly summarized next.

Caregiving Literature

The future of adults with DD is a source of anxiety for aging caregivers. 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 concerns. Future planning is an important process and is closely associated with caregiver well-being (Smith & Tobin, 1993). In the DD caregiver literature, there are mixed findings regarding the well-being of caregivers versus non-caregivers. However, most studies suggest that emotional and physical well being of DD caregivers are equal (Chen et al., 2001; Seltzer et al., 2001) or better (Singer, 2006) as compared to non DD caregivers. This is somewhat surprising because in the general caregiver literature, caregivers' emotional and physical health were at risk compared to the general population (Pinquart & Sörensen, 2003). For example, substantial differences between caregivers and non-caregivers were found in psychological health (i.e., levels of depressive symptoms, stress, self-efficacy, and general subjective health) than physical health. Researchers suggested several explanations as to why sometimes DD caregivers report equal or better emotional health compared to non-caregivers. These explanations include the need to remain healthy and becoming caregivers earlier in their lives. However, most of the literature on DD caregiver focuses on parents of younger children with a developmental disability. As caregivers age, additional consideration should be given to their own personal health, their ability to provide ongoing care, their concerns over future caregiving, and the aging of the person they are caring for.

Several initiatives have been developed to help aging caregivers in planning for the future (Susa and Clark, 1996; Etmanski, 1997; Botsford and Rule, 2004; Heller and Caldwell, 2006). Generally these initiatives focus on giving families the tools they need to develop a future care plan. One intervention, which adopted a peer support model and included adults with DD in the planning process, was successful in assisting families to complete letters of intent, take actions on residential planning and develop a special needs trusts (Heller and Caldwell, 2006). This intervention led to decreased caregiving burden and increased opportunities for daily choice-making of adults with DD. Future care planning also had a positive effect on caregivers' emotional wellbeing. However, despite evidence of the positive effects from future care planning, some caregivers still do not. What remain unknown are the factors that "contribute to" or "discourage" caregivers from making plans for the future care of their family member. In order to support caregivers through this process, more information is needed about the triggers or barriers to planning for the future. In addition, learning about the success stories will also help to develop appropriate services and supports for caregivers and persons with DD as they age. In the Older Caregivers and Transitions Study (OCAT), close attention is paid to the emotional responses from caregivers as well as the potential barriers to future care planning.

Arizona Town Hall Meetings

In the Fall of 2000, town hall meetings were organized in Pima County to understand the needs of older caregivers. Some of the topics discussed are listed below:

- Outlying and rural areas: more social opportunities, availability and costs of transportation
- Support coordinators (SC): availability, quality of SCs
- Guardianship and Conservatorship: pros and cons, costs of process
- Respite services: appropriate use and time for respite, availability of providers, list of providers, recruitment of respite personnel
- Future planning: assisting persons with disabilities to plan for themselves, how to access information about alternative living arrangements
- Resources: where to call in an emergency, getting help from DDD, who provides staffing in homes

Part Two: METHODOLOGY FOR THE OCAT STUDY

Recruitment

The Sonoran UCEDD research staff received support and direction from its program director as well as several local agencies/organizations that have well-developed relationships within the local disability community. Recruitment for the OCAT study began in the summer of 2007 and by the end of March 2008, the research staff met with 30 caregivers individually or during one of two focus groups. Participants lived in Coconino, Maricopa and Pima County. Recruitment was facilitated with help from the Arizona Department of Economic Security's Division of Developmental Disabilities (DES/DDD), Arizona Governor's Council on Developmental Disabilities, Pima Council on Aging, and several statewide advocacy groups in Phoenix, Flagstaff, Tucson, and Sierra Vista. Flyers were disseminated through individuals, support coordinators, the Artworks day program, and community health centers. Interested participants contacted the research staff for more information and were scheduled to participate in their choice of an interview or focus group. Caregivers had the choice of participating in an individual interview or a focus group.

To be eligible for the study, participants had to be 50 years and older and caring for an individual with a developmental disability. The caregivers were providing direct care in activities of daily living and or providing support and monitoring in an informal or unpaid capacity. Caregivers were not formal or paid caregivers. The caregivers may also be the legal guardian but this was not a criterion for participation. The interviews were conducted in the caregivers' homes or a private office, and the focus groups were held at a convenient site in their respective community. A total of four focus groups were scheduled, but two of the four (Flagstaff, Phoenix) focus groups were changed to individual interviews due to the small number of participants. A total of 22 interviews were conducted and 8 caregivers participated in two different focus groups (Pima and Coconino County) for a total of 30 participants.

Data Collection Process

The data collection process involved several steps. Prior to the interview, all participating caregivers read a detailed consent form that explained the purpose, procedure, and potential risks/benefits of the study. Participants also completed a survey regarding their current caregiving situation, caregiver's health, and the health of the person receiving care/support. The principal investigator and/or trained research assistant utilized semi-structured, open-ended interview questions for each in-depth interview and focus group. The questions focused on the current caregiving situations, including any difficulties faced by the caregiver in providing care; health changes in the caregiver (CG) and care-recipient (CR); prior experiences related to caregiving or residential settings; and concerns regarding planning for the future care of the CR with a DD. The interviews and focus groups each lasted approximately one to two hours. All interviews and focus groups were audio recorded with permission and later transcribed. Participants received a small stipend for their participation. To enhance data collection, the research staff wrote field notes to capture participants' behaviors and expressions and to record the interviewers' own reflections.

Analyses

All transcribed interviews and focus group discussions were coded and analyzed with qualitative data analysis software (*Atlas.ti 5.0*) by the trained research staff and a pre-med student doing a summer research internship. Content analysis was applied to interpret the interview data. The content analysis process involved identifying significant statements and grouping them into meaning units or themes. In order to increase the reliability of coding among three trained coders, the written codes and their definitions were constantly compared during the initial coding process and creation of themes. As a cross-check for intercoder agreement, independently derived results developed by different coders were compared on randomly selected interviews.

Results

Demographics of Caregivers (CG)

The family members who were part of the study provided care for their family member with DD ranging from: supervision of living arrangements, finances and service providers to more daily and intimate care such as toileting, feeding and dressing.

The demographic survey caregivers completed prior to their interviews or focus groups contained demographic information about the caregiver (CG) and care recipient (CR) regarding their general health status and medical conditions, residential arrangements, and DDD and other service involvement. The following table provides demographic information of our participants.

Age:	47-84 years old (age limit was reduced for one caregiver)
Gender:	Females (23) Males (7)
Ethnicity:	African American (1) Hispanic/Latino (3) Non-Hispanic White or Caucasian (26)
Length of Time Providing Care/Caregiving:	9 – 56 years
Reported Health of Caregiver:	Poor to Good (30%) Good to Excellent (70%)

Caregivers mean annual household income was between \$45,000 and \$60,000. Educational levels ranged as follows: 9 had graduate or professional degree; 7 had a 4-year college degree; 9 had some college or vocational/technical school education; and 4 completed some high school education or less. In the past year, 25 caregivers reported health changes that included: decreased energy, sensory loss, difficulty with memory, and decreased physical ability or mobility.

Demographics of Care Recipients (CR)

The following table provides general demographic information about the care recipient.

Age:	14 – 66 years old
Gender:	Female (28) Male (18)
Ethnicity:	African American (1) Hispanic/Latino (4) Non-Hispanic White or Caucasian (27)
Reported Disability (can report more than one disability per person):	Mental Retardation (25: mild = 7, moderate = 9, severe = 6, profound = 3), Cerebral palsy (11), Autism (5), Epilepsy (5) Other (12)
Residential Setting of Individuals with DD:	Living with caregiver: parent (18) Living in own home/apartment by themselves (4) Living in own home/apartment with or without a roommate with care/supervision provided by agencies/ IDLA (5)* Living in group home (3)* * supported settings

The reported educational level of the care recipients was: 18 completed high school (five through special education); 4 completed some high school education; 1 completed some college or vocational school; and one reported none. Of the 30 CRs, 28 were involved in some type of DDD funded programs, such as day programs. Employment status of the care recipient was not formally collected but through the interviews we estimate that less than 5 individuals were employed at the time of the interview with their caregiver.

Caregiver Interviews: Themes

Participants in this study were eager to share their stories and thoughts about their daily routine and long-term role as a caregiver. Although each situation is unique and diverse, the research staff found several consistent themes throughout our interviews with older caregivers. For this project, we defined an older caregiver as 50 years of age or older. The age cutoff was set to enhance recruitment and to encourage participation by parents, grandparents, and siblings. This by no means reflects the staff's opinion on what is considered an "older person." Our sample of caregivers may be small in relation to the number of caregivers in Arizona, but the in-depth nature of the interview allowed us to better understand the issues that were of deep concern and importance to caregivers.

After close review of each interview, the research team identified five themes that are listed below. The following paragraphs explain in more detail the five themes that were prominent in our interviews and focus group discussions.

- 1) What causes a family member to start planning for a future where they are less involved: **Future Care Planning: Components, Timing, and Triggers**
- 2) What **Psychological and Emotional Responses of Caregivers** impact their ability and willingness to plan for the future
- 3) What are the Caregivers' **Concerns, Challenges, and Successes** (quality of life, etc.)
- 4) What role does **Resources and Systems of Care** play in successful transition planning?
- 5) How does the **Health and Health Care Delivery System** impact transitions and ability to be a caregiver?

1. Future Care Planning: Components, Timing, and Triggers for Transitional Planning

Components

Future care planning involved several components, decisions, and processes in order to meet the future care needs of persons with a developmental disability. The components and decisions included: having adequate financial resources necessary to provide care; developing a trust fund (if resources allow); identifying alternate caregiver(s); finding an appropriate residential setting; and transferring decision making and/or advocacy powers. Some decisions were easier than others but still difficult, time consuming, and costly. The decisions made affected not only the

caregiver but also the person receiving care and other family members. Change was difficult for all.

Timing

Caregivers could not anticipate when it was the “right time” to make plans or to start the discussion. They knew it had to be done but often needed help or direction to start the discussion about future care plans or transitions. The timing for making future care plans was different and unique based on the caregiver’s health and age, the care recipient’s health and maturation, past experiences, available family and community supports, and the sense of urgency related to one’s disability or death of a caregiver. Yet for some, an incident may have occurred and it felt like the right time for the person with DD to move out of the family’s home; to find a roommate; to increase independence; and to try something new. For most, these decisions consisted of taking small steps, failing and trying again, and enlisting the help of experts and close confidants. This process occurred over weeks, months, and even years. Caregivers shared the following experiences that helped them to move forward in making future care plans:

Triggers

- **Family Member with DD Increased Independence.** As the care recipient ages and matures, their behaviors reflected a growing need for independence. The parental role changed from being the person to monitor, restrict, and correct behaviors to being one who provided encouragement and guidance. Caregivers viewed transitional care planning as part of their child’s growing up process, their need for increased independence, and an opportunity to learn new skills. This process was initiated by both caregiver and care recipient. Both the caregiver and care recipient had to be ready for a change. Some care recipients themselves initiated the idea of moving out.
- **Caregiver Exhaustion/Inability to Continue.** Several caregivers expressed their exhaustion and inability to continue in their current role and situation. For single parents, it was difficult to be the sole care provider on a day-to-day basis. As their child grew older and larger in physical size and weight, it became more difficult to manage certain behaviors related to their disability. It became unsafe or uncomfortable to participate in certain activities with their child. For example, a mother providing bathing assistance to an adult son, or aggressive behaviors on the part of the person with DD.
- **Family and Friends Urging.** Other family members also encouraged the primary caregiver/parent to consider alternate living arrangements. Siblings or relatives viewed change as benefiting both parties. For the caregiver it would allow more time to take care of their own needs and for the person with DD it was an opportunity to make new friends, connections, and to broaden their skills.
- **Past experiences.** For older caregivers who lived through the period of deinstitutionalization, it appeared to be more difficult for them to accept alternate living arrangements or additional assistance. The experience of having a family member in an institution brought back difficult memories and caregivers were fearful of making a

decision that would again lead to poor care. Their negative or ambivalent responses were based on bad experiences; the lack of options in the past; and lack of information.

- **Dependence.** For caregivers who are older and alone, their family member provides companionship and assistance with daily chores. Over the years, they grow dependent on each other.
- **Death .**The death of a family member or caregiver also forced a transition. This was typically the most dramatic transitional change. It involved other family members learning new roles as caregivers, guardians, and advocate. This transition continued and evolved over time as family members dealt with immediate and long-term needs.

In our sample, financial planning including creating trust documents were the most frequently formalized components of the care planning process. For those families interviewed who had not instigated any other planning components for the individual with DD, such as living arrangements or substitute guardians or advocates, it appeared that the psychological and emotional responses of the caregivers combined with the lack of availability of appropriate community supports and services was the major barrier to future planning. What can hinder the process of addressing the other components were the psychological and emotional responses of caregivers and the availability of community supports and resources.

2. Psychological and Emotional Responses of Caregivers

Caregivers spent a lengthy portion or the majority of their lives focused on meeting the needs of their family member with a developmental disability. The caregiving role continued despite where the care recipient lived; having financial security; the age of the person needing care; and the involvement of community agencies or programs. Caregiving not only required time and attention but creativity and resilience.

Caregivers did not complain about their role but expressed other emotional responses that we felt were important to highlight. These emotional responses may provide at least a partial insight to why comprehensively planning to transition care to others is so difficult. In our interview transcripts we identified several emotional responses experienced by caregivers. The most commonly expressed emotional responses revolved around trusting the individuals involved in one's care; frustration regarding the system of care and availability of trained care providers; the hope and preference for a safe and caring environment; and concerns about abuse, neglect, and exploitation. The main emotional state preventing comprehensive future transition planning was the worry about the safety and well being of the loved one if the family member gave up their role.

Caregivers were consistently concerned about the safety and well being of their loved one while in the care of others. They were hoping that trained, knowledgeable, and caring individuals were providing the care. At times that was the case, but more often they were frustrated at the quality of care providers that were employed by agencies and group homes. For some caregivers, care and respite were provided in their home. In this situation, caregivers had to relinquish control

and allow complete access of their home to different care providers. Caregivers felt vulnerable and had no choice but to trust individuals who came to their home. If caregivers had a negative experience, it made an impact on their future decisions and emotional wellbeing.

Caregivers were fearful of inappropriate physical and sexual behaviors by staff in residential settings; exploitation and theft; lack of attention to pain and discomfort experienced by the person with DD when something is wrong; and social isolation. The caregiver's realization that they could not expect to find another individual beside him or herself who would have the same level of concern and commitment for the welfare of their loved one was very painful. Some caregivers believed that peace of mind was not attainable unless the caregiver lived longer than the person who required care. When one problem was resolved, another appeared. Caregivers had to plan ahead, had to be ready for any change or crisis, and often feared what the next day would bring. It was often an emotional roller coaster.

One might be tempted to assume that if a person with DD moved out of their home, the stress caregivers experienced would decrease. That was not necessarily the case. For some, the stress and anxiety increased before it decreased. For others the caregiver role changed from being a parental figure or guardian to one of monitor, friend, and case manager. Despite the living arrangement, caregivers continued to play an active role in the life of their family member and continued to experience a wide range of emotional responses.

3. Concerns, Challenges, and Successes

For many caregivers, their work and social schedule revolved around medical appointments; running errands to buy necessities; and frequent visits or phone calls to their family member with DD (if s/he was living out of the family home). They were always accessible by phone or close proximity in the event of an emergency. The time that they set aside for themselves and their needs were often limited. Taking a short vacation alone or with others was often a luxury. Taking an extended vacation required careful planning and was often accompanied by hesitation and ambivalence.

One important and consistent concern and challenge revolved around maintaining the "quality of life" for the person with a developmental disability. Maintaining one's quality of life involved several components and were identified as:

- Being social integrated through participation in different activities and programs
- Finding the "right" care providers who are trustworthy, well-trained, compatible, and caring
- Having one's basic needs met with proper nutrition, exercise, and ongoing stimulation
- Having employment that is meaningful, valued, fun, and interesting
- Maintaining a nice appearance with appropriate clothing, good hygiene and grooming
- Maintaining old relationships and developing new ones

- Integrating the person with DD into decision making, taking into account their dislikes and likes
- Living in a safe environment where the individual with DD is free to voice their concerns
- Learning new skills that promote independence
- Being around people who enjoy your company

Caregivers consistently mentioned the lack of available and trained staff that in residential settings as well as those who provide in-home supportive services for the caregiver or the care recipient. Caregivers held the following views:

- Positions were filled with individuals whose first language was not English thus making communication more challenging, not only for the caregiver but most importantly for the care recipient who may have communication challenges of their own. (English was the primary language of all caregivers interviewed, clearly for monolingual Spanish speaking families there may be different challenges) There was high turn over in staff due to low-wages. The most qualified and skilled staff soon found other employment.
- Some staff appeared to approach their job as a way to pass time instead of taking a real interest in their role and how they were interacting with the resident or individual in their home.
- Staff appeared to receive little to no training for their position. This becomes particularly problematic if the person is from another culture or country. With inadequate training, the risk for abuse and neglect can increase due to the lack of understanding regarding difficult behaviors and how to find alternate ways to deal with these behaviors.
- The goal for some residential programs appeared to be business-driven versus consumer-driven.

Group homes were an option for persons who were not able to live alone or with roommates in an independent setting. Some caregivers had negative experiences with group homes. In some cases, supervision and training of staff was considered inadequate and accountability and oversight was minimal. The potential risk for abuse and neglect was also a concern. Choosing the right group home was a difficult decision that required a lot of the caregiver's time before, during, and after the move. Nursing homes were seen as the last resort and were viewed as institutional type settings. The biggest fear for one caregiver was that their child would be lying in bed with the TV blaring. In settings like these, caregivers felt that individualized needs could easily be overlooked.

Caregivers also expressed concerns over whether a family member should try to obtain guardianship when the person with DD required minimal assistance in day-to-day activities but help with more complex decision making. There was a fine line between respecting the individual's need for independence and ensuring their financial and physical safety. An individual may not need a guardian but a person with DD still needs an advocate. Caregivers were concerned about their child being vulnerable. For example, their child may sign documents or participate in activities without a complete understanding of the responsibilities involved or the potential outcomes.

There were several examples of successful transitions and future care planning. Table 2 showed that 4 care recipients lived alone in their own apartment/home and 5 lived in their own home/apartment with or without a roommate with care/supervision provided by agencies. For some, the move was easier and smoother than anticipated. When the caregiver and their son/daughter were ready to move out of the home and have a roommate, one of the most important steps was to find a compatible roommate. This took careful planning and screening and for some it required matchmaking help from others who knew the potential roommates. Compatibility was also important when finding staff help. This was an important and necessary element to successful transitions and care.

Caregivers and their families were constantly engaged in problem solving and they were always anticipating potential problems and solutions. Successful transitions and changes impacting the care recipient required close monitoring and ongoing revisions. Here are additional examples of what caregivers did in order to have a more successful outcome.

- Caregivers taught and empowered their child to speak up and know when something is not how it is supposed to be, when it was wrong or inappropriate.
- Siblings who assumed care learned how to be a guardian and found the right balance between being hands on and staying at arm's length. Programs preferred that caregivers stay at arm's length. Success depended on "paying attention and staying focused on it."
- Caregivers assumed the role of teacher and trainer so staff developed the necessary skills to keep the person with DD engaged and stimulated.
- Caregivers found wonderful care providers through careful screening and help from others.

4. Resources and Systems of Care: Family, Hired Care Providers, and Corporations

Caregivers utilized resources and systems of care to different degrees in their daily lives and looked to these systems and resources for future transition planning as well. Most families counted as resources: family and friends; case managers/support coordinators and paid service providers. If the caregiver was more familiar with the system and services available or if they had an advocate within the system, they were more likely to utilize these resources when needed. Yet, even with this knowledge, caregivers still faced challenges along with their successes.

Family and friends were frequently considered an important resource when the primary caregiver needed a respite, had another emergency to attend to, want to go on vacation, or was unable to provide care temporarily or permanently. For caregivers who had relatives out of town or out of state, it was more difficult to see them as a resource or permanent future caregiver. Caregivers preferred to keep their family member in the city or geographic area where they were familiar or had an existing support system. When it came to long term planning, there was increased hesitation and doubt about a relative's ability to become the primary caregiver. Despite family members offering to care for the individual with DD or become more involved in providing

oversight of the care in the future, there was still hesitation on the part of the caregiver. Caregivers did not want to place a burden on other family members. Caregivers also felt that the family member(s) or relative:

- Did not truly appreciate how their own lives would change and the impact on others in their family.
- Had not spent any length of time with the person with DD and therefore did not understand the degree and amount of time and commitment it required.
- Did not fully understand the details involved when working with the various systems of care.
- Would do a good job for as long as they could but it may come to a point where they have to make other arrangements. The primary caregiver did not want to place any guilt or sense of obligation on them or prevent them from making other plans.

At the same time there was some comfort in knowing that family would probably be better than someone with no prior relationship or commitment. For caregivers without family there was a deep fear of the unknown and worry regarding who would provide the appropriate care for their loved one. This caused a high level of stress for one particular caregiver who could only hope that things worked out well.

In addition to immediate family members, caregivers relied frequently on the assistance they received through DDD funded services and/or additional hired caregivers. The majority of caregivers received help from the DDD system but a few had hired private caregivers on their own. The study did not differentiate between consumers who were ALTCS (Arizona Long Term Care System) versus state only DDD eligible. The care providers were viewed as an extension of the family because of their close involvement. If the care recipient lived outside of the home in either a group or independent living arrangement, caregivers became acquainted with several individuals who rotated providing care. This was a challenge because caregivers had to re-orient and teach each new staff member about:

- A person's routine, likes, and dislikes
- Ways of preferred communication, especially if a person is non-verbal
- Technological devices for communication, mobility, etc.
- Subtle changes in behaviors that may be a sign of pain or discomfort
- Necessary dietary restrictions due to medical conditions

Caregivers interviewed received a variety of services including: home or community based attendant care, housekeeping, respite, or other support options to help persons with DD live independently in the community. Services were often limited and caregivers had to be vigilant about asking for the necessary help. Even if caregivers were eligible for services through DDD and the Arizona Long Term Care System (ALTCS), this did not automatically mean that they received the help and support they requested. Despite the availability of services through DDD and AHCCCS, caregivers felt resources were still inadequate. The timely availability of respite services was an area of concern and frustration; getting medications approved by AHCCCS;

accessing reliable wheelchair transportation; dealing with turnover of support coordinators that resulted in delayed meetings or services; and waiting for residential funding to come through DDD were areas of frustration.

Caregivers were resourceful and sought out information from other families, their support coordinator, day program staff, and community agencies. At the time of the interviews, most of the individuals with DD had already left/aged out of the school system. While persons with DD were in school, caregivers were more connected and had additional contacts and sources of information. Once out of school, caregivers felt that their options became limited and they became more isolated.

Stable situations changed at any moment and new plans had to be made. For example, if a paid care provider quit or found a higher-paying job, it sometimes took months to find another compatible and trained replacement. Sometimes new programs were developed and they were managed well in the beginning but over time the quality of services decreased under new management. Again, compatibility between the care recipient and care provider was a very important ingredient for success and this was often challenging.

5. Health and Health Care Delivery

Although the focus of the study was on caregivers, our interviews inquired about the health concerns of both the CG and CR. Caregivers described their current health as good to excellent but there were concerns about their energy level and ability to keep going. Caregivers voiced that they simply had to find a way to keep going and provide the necessary care. Finding time to relax and replenish themselves was often a challenge. Caregivers possessed a drive and determination to keep going and to stay strong and healthy so they can continue their role as caregiver and advocate. There was indication that some caregivers minimized their own health concerns and delayed their health care needs.

During the interviews, caregivers shared their concern regarding the health of their family member (CR). The health care concerns included:

- Weight, food, and nutrition monitoring
- Chronic conditions such as diabetes and digestion problems
- Dental issues that included having no teeth and preventive care
- Age related health conditions such as: thyroid conditions, eye terigiums, hormonal changes
- Age related changed regarding energy level and function
- Psychiatric medications not working any more
- Close monitoring of medications
- Sexuality and appropriate sexual relationships
- Hygiene, cleanliness, and lack of exercise

- Down's Syndrome and Alzheimer's
- Mental health mood swings and depression
- Unresolved conditions such as stomach pain, dental pain, bone fracture, and gall bladder problems
- Health care coverage

When accessing health care services caregivers often faced care providers or staff who were unaware of the complexities and pre-planning that occurred even prior to a medical appointment. Pre-planning involved adjusting one's routine and schedule prior to the appointment, transportation needs, and work accommodations.

Caregivers also experienced a wide range of other problems related to health care such as:

- Long waiting times for getting a medical appointment and waiting times in the clinic were especially difficult for an individual in a wheelchair
- Transportation arrangements to and from appointments had to be carefully planned with consideration for the safety of the caregiver and care recipient
- Interacting with providers who didn't understand that some of the challenging behaviors exhibited by the person with DD were associated with a medical condition or reactions to the environment
- Having to be persistent when medical conditions were not easily resolved
- Trying to convince health care providers that something was physically wrong when the person with the disability could not communicate verbally but was acting out physically
- Making sure that medications were given appropriately and changed when no longer effective
- Dealing with insurance companies and preauthorization

Part Three: DISCUSSION

The following comment vividly shares the difficult journey of one caregiver.

“I wouldn't wish what I've been through on anybody and I think there was a lot of judgment from society, from providers, from entities and agencies. I think overall, there is no right and wrong answers, but when we find, when a family finds the answer that they are willing to try, I think they need as much support in that in a non-judgmental way. If the answer that they try they find isn't working and is too uncomfortable for whatever reason and they want to try something else, it's our job as a society to help support that until they can find what will help them become whole and heal from the experience of having the rug pulled out from underneath them.”

The experiences of caregivers were diverse and rich. We examined the reality of what caregivers experienced and found that their experiences were constantly changing, the journey was exhausting, it was difficult to think about the future; and there were inadequate resources for caregivers and persons with developmental disabilities regarding future care planning. The caregivers interviewed were resilient and resourceful. One thing was clear – the caregiving role was not time-limited and required an enormous amount of attention and energy. It begins with the birth of the child and ends only upon their child’s death. The reality that a care recipient will outlive the person with DD can be frightening and can cause distress and anxiety. Respecting individual circumstances and differences, this study highlights the importance of 1) addressing caregiver wellbeing, 2) availability of trained staff and care providers, 3) engaging support systems and systems of care in future care planning, and 4) emphasizing healthcare for caregivers and persons with DD.

Caregiver Emotional and Physical Wellbeing and Support

Some older caregivers were exhausted from the constant need/desire to stay-on-top of things; many don’t even know the questions to ask when looking for alternate residential settings or services; and others would like to “have somebody coaching them on how to do this (future care planning).” For caregivers, there was a need for ongoing and up-to-date information, education, and support - before, during, and after future care plans are made.

When you spend a lifetime or a period of time together, you understand a person’s day-to-day behaviors. You are aware of their habits, likes and dislikes, subtle changes in behaviors, responses to pain and discomfort, alternative ways to communicate, and ways to engage them. This understanding comes from a deep sense of caring, from paying close attention, and from exploring alternate strategies until you find something that works. It also requires knowledge about a person’s disability and well as their abilities. Instead of focusing on a person’s disability family members focused on the abilities of their family member with DD.

Support coordinators played a key role in the provision of support and services. The caregivers in this study were generally satisfied with their current support coordinator. If they were not satisfied or comfortable with a support coordinator they were assigned, they requested or were reassigned to a different person. When reassignment was uncomfortable or difficult, caregivers turned to alternate supports like peers and family members. When a service provider or advocate went out of their way to do something positive, caregivers were very appreciative of the help they received. Families were looking for the appropriate “care coordinator,” “case manager,” “mentor,” and “advocate.”

Caregivers sought out individuals for guidance and information. This could be the support coordinator, someone at their day program, a therapist providing treatment, or another family member with a child with DD. When caregivers need answers, they need it now and they sought out someone they trusted and felt comfortable with.

Recommendations:

The ability to facilitate transitions and to support caregivers in making future care plans takes a collaborative effort in Arizona between DES, DDD, service providers and the University of Arizona Sonoran UCEDD. We need to ensure that persons working with families and individuals with DD know how to bring up and address the concerns of caregivers, particularly those who are aging. As a collaborative unit, we need to:

- Provide information and trainings about the components to consider when making future care plans. Information needs to be accessible in different formats: written, web, verbal, video
- Educate care providers and support coordinators about the emotional responses and concerns that caregiver face when planning for the future care needs of the person with DD and how to address these barriers
- Provide support groups and other opportunities for families to talk about their emotional responses to aging and transitioning caregiving
- Regularly introduce the topic of future care planning with families and not assume that there is a perfect time to do so
- Identify caregivers who may need additional assistance and support during this process
- Create high-risk indicators that can assist service providers in identifying caregivers that may need additional assistance
- Train support coordinators and mental health professions to screen for caregiver stress and wellbeing
- Develop a peer support system in which knowledgeable peer parents can walk other caregivers through the appropriate steps, thus utilizing the expertise of others

Availability of Trained Staff and Care Providers to Improve Accountability

The most difficult issue for older caregivers to resolve was finding the right person who will be available on a consistent and timely basis to advocate for their son/daughter/sibling/grandchild.

Recommendations:

Training is already occurring independently within programs and systems of care. In times of limited resources our community (DES, DDD, service providers, Sonoran UCEDD) can:

- Work as a collaborative unit to identify and design appropriate trainings
- Pool together resources and make training more accessible
- Include caregivers and care recipients in identifying and developing the necessary training sessions
- Support and expand caregiver training programs/certification programs and reward persons who complete these
- Increase wages for individuals who show commitment to providing quality and respectful care

- Educate the public about the shortage of qualified care providers

Engaging Support Systems and Systems of Care

It was encouraging to hear about successful transitions that promoted independence. There were examples of competent, trustworthy, and caring staff and care providers. Many of our caregivers continued to be active advocates for persons with disabilities in our community on a local and state level. Some saw themselves as the fortunate few who had additional knowledge about how the system works or how to access appropriate services and benefits. Yet other caregivers did not know what was available or how to access information. Knowledgeable persons are needed to walk caregivers through the appropriate steps. Utilizing the experience and expertise of others and making this information readily available will be helpful and useful.

The fact that the majority of future care plans were not formalized highlights the need for all systems of care to understand what is involved in making future care plans. There must be a coordinated effort in the delivery of services. There is a statewide effort to coordinate and share information between the Aging service system and the Disability service system. These efforts must continue and expand. The service system and programs involved with our DD community can join together to ensure that families, individuals with DD, and DD service workers have the information and resources they need to create a system of competent, caring supports for people with DD as they and their caregivers age.

Recommendations:

Caregivers are a valuable resource and their ideas and contributions should be recognized. The town hall meetings held in 2000 identify consistent concerns that need to be addressed. Ongoing public forums with caregivers, community agencies, AHCCCS, DDD, advocates, and persons with DD can facilitate dialogue and identify both short term and long-term solutions. The following represents future topics of discussion.

Caregivers have expressed the need to explore the following:

- Pool together information about useful, trustworthy, and dependable resources that have been carefully screened
- Increase accountability of staff and programs by a reporting system that is fair with clear guidelines
- Reward programs that do a good job
- Assist programs that do a poor job
- Continually educate the public about the growing demand for appropriate housing for persons with DD
- Educate the public and systems of care about aging and disability related issues
- Develop accountability measures and assessments so consumers can clearly examine and understand what they can expect from service providers

Healthcare for Caregivers and Persons with Developmental Disabilities

As identified earlier, caregivers had several healthcare concerns. Healthcare education and training for healthcare providers can address these illness related concerns as well as explore one's comfort and attitudes about working with persons with disabilities. Our changing demographics highlighted the growth of older persons so we need to address aging related changes for persons with DD. We can take advantage of the knowledge gained by other UCEDD programs that focus their research efforts in this area. Knowledge about community resources, DDD system and services, and assistive technology would facilitate appropriate referrals and coordination of care.

The Sonoran UCEDD is actively integrating disability related topics and innovative teaching strategies into the medical school and health science curriculum for students as well as physicians in their family practice residency program. At a family medicine clinic at UPH K campus, the Sonoran UCEDD has developed a Medical Home for adults with disabilities that emphasize coordinated and continuous care. Through efforts like these, we can begin to education the community and well as health care providers.

When providing healthcare it is important to seek out and integrate the person with DD and the caregiver(s) into the care plan. As appropriate, healthcare providers must also incorporate and communicate effectively and efficiently with other service and healthcare providers in order to ensure a coordinated effort to improve the health and lives of persons with DD. We must regularly assess and explore the physical, emotional, and spiritual health of caregivers.

Next Steps for the Aging and Transitions Project

Based on what we learned from our OCAT study and from input from administrations within the Division of Developmental Disabilities, the research staff designed two follow-up projects. During the summer of 2008, an online survey was disseminated to all support coordinators statewide through DDD. This survey translated some of the lessons learned and explored the important role of support coordinators throughout Arizona. The objectives were to identify support coordinators' roles in future care planning and their knowledge about aging related issues. The goal was to identify potential training needs and to promote effective transitional care planning policies. Over 100 support coordinates completed the survey and the analysis is currently being conducted.

The second project is a survey that was designed to assess the knowledge and comfort health care providers and clinic staff possess about caring for person with a developmental disability. This survey will be implemented at the University of Arizona's Family Medicine clinics at two different sites. The outcome will assist in the development of training modules for health professionals that can be utilized in these settings and elsewhere. It will also complement the goals of the Sonoran UCEDD Medical Home at UPH Kino

Abbreviations

- ADD: Administration on Developmental Disabilities
- ATP – Aging and Transitions Project
- DD – Developmental Disability
- DDD – Division of Developmental Disabilities
- CG - Caregiver
- CR – Care Recipient
- OCAT – Older Caregivers and Transitions
- UCEDD – University Centers for Excellence in Developmental Disabilities Education, Research, and Service

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Research Staff

Lynne Tomasa, PhD, has been with the Department of Family and Community Medicine (FCM) since 1987 and is involved with geriatrics/gerontology education, program and curriculum evaluation, and research in aging. As the project leader, Lynne combines her social work and teaching experience with her interests in health care, end of life issues, long term care planning, and caregiving.

Yumi Shirai, MS, is a research assistant with the Department of FCM and a doctoral student in Family Studies at the University of Arizona. She also works at Artworks, a professional artists' studio and day program for people with developmental disabilities. Yumi's doctoral study focuses on the psychological health of older caregivers. This project combines Yumi's field experience and her academic interests.

Natasha Bhuyan, is currently a first year medical student who completed a summer research internship in 2008 with Lynne Tomasa and Yumi Shirai. Natasha is interested in geriatrics when she completes her medical education and residency training. During her internship she spent time at the Artworks day program.

Administration

The principal investigator for the Administration on Developmental Disabilities grant is Tamsen Bassford, M.D, Chair of the Department of Family and Community Medicine. The Director of the Sonoran UCEDD is Leslie Cohen, a long-time disability advocate with extensive experience in the developmental disabilities field in Arizona. Leslie is also the former Executive Director of the Arizona Center for Disability Law.

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