Older Caregivers and Transitions Study

Aging and Transitions Project

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Promoting effective transitions for older caregivers and people with intellectual and developmental disabilities (I/DD) is a core goal of the Sonoran UCEDD. The five-year Aging and Transitions Project (ATP) encompasses several activities, including data collection to inform future program planning and advocacy. ATP goals are to describe and address barriers to effective late life transitions for older caregivers of people with developmental disabilities; to promote effective late-life transitions for adults with developmental disabilities; and to improve aging-related and end-of-life care for people with intellectual and developmental disabilities. The first activity, a research project, interviewed older caregivers in order to learn about the issues they face when planning for the future care needs of their family member. This project, Older Caregivers and Transitions Study (OCAT), is described in this article.

Importance of the OCAT Study: Our Changing Demographics

The older population is growing significantly, living longer and getting older itself. Approximately one in eight, or 12.4% of the population, is an older American. By 2010 the population 65 and older is expected to increase to 40 million and then to 55 million in 2020 (Greenberg/AoA, 2007). In addition, the increased longevity of individuals with an intellectual and development disability (I/DD) will directly impact the need for and type of services and supports needed. National estimates reported by Braddock (1999, 2008) and Fujiura (1998) indicate that the majority of people with developmental disabilities in the United States reside with family caregivers. Approximately 25% live with family caregivers who were over 60 years of age. State by state estimates of residential services for people with I/DD can 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 terms of actual numbers, an estimated 15,923 persons with I/DD lived with an older caregiver in Arizona during 2006 (Braddock et al. 2008).
**Methods: Data Collection**

To assess the changing demographics and the diversity of Arizona’s population, the Sonoran UCEDD implemented the OCAT study. This is the first research activity that is part of the larger Aging and Transitions Project, the goal being to learn about the issues, challenges, and successes that older caregivers face when providing support and planning for the future care needs of a family member with I/DD. This study, approved by the University of Arizona Human Subjects, involves caregivers over the age of 50 who provide care and support for a family member with I/DD.

In the summer of 2007, the research staff began interviewing caregivers over the age of 50. Recruitment occurred with the assistance of the Division of Developmental Disabilities and various community organizations and programs that support people with I/DD. By the end of May 2008, the research staff had interviewed 30 caregivers individually or during focus groups. Participants lived in Coconino, Maricopa and Pima County. See table for participant demographics.

**Research Findings/Results**

Older caregivers in this study were very committed to providing high quality care that focused on supporting the independence and dignity of their family member. Future care planning was primarily directed by the older caregiver(s) and involved other family members to varying degrees. Discussion about the future care needs of the person with I/DD occurred over a period of time and involved decisions about financial resources like trust funds; moving to another residential setting; the identification of appropriately trained formal/hired caregivers; and identification of a future guardian or monitor. In our sample, financial plans were the most frequently formalized component of the care planning process. The majority of the discussion around future planning was not formalized or written down for others who may become involved in providing support when the older caregiver was not available. Several themes were identified—prominent themes included:

- timing or triggers that led to future care planning;
- psychological and emotional responses experienced by caregivers;
- important quality of life issues for the person with I/DD
- challenges faced when making future care plans
- being an advocate
- desire to have more information.

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<th>Demographics: Total Participants = 30 Caregivers</th>
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<td>Age:</td>
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<td>Individuals with I/DD:</td>
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Discussion

Many of our caregivers have been and continue to be active advocates for people with disabilities in our community on a local and state level. Some see themselves as the fortunate few who have additional knowledge about how the system works or how to access appropriate services and benefits. Some older caregivers are 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).” The most difficult issue for older caregivers to resolve is to find the right person who will be available on a consistent and timely basis to advocate for their son/daughter/family member. For caregivers, there is a need for ongoing and up-to-date information, education, and support — before, during, and after future care plans are made. The Sonoran UCEDD will use the information collected and the valuable insights of caregivers to advocate for the needs of people with I/DD and to develop helpful informational tools and training for families and service providers.

Future Activities

The next research study was designed based on the information learned from our older caregivers and from input from administrators within the DDD. This activity translates some of the lessons learned and explores the important role of support coordinators at DDD. In June and July, support coordinators throughout Arizona will be invited to participate in an on-line survey and focus groups. The objectives are to identify support coordinators’ roles in future care planning and their knowledge about aging related issues. The goal is to identify potential training needs and to promote effective transitional care planning policies.

We want to thank all the families who shared their experiences; the programs that support people with I/DD; the Arizona DDD; and the Arizona Center on Aging for helping the research staff design, implement, and learn from this project. A more detailed report will be available in the near future.

References


**About the Research Staff**

*Lynne Tomasa, PhD*, has been with the Department of Family and Community Medicine (FCM) for 20 years 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. 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.

**Web Resources on Caregiving and Aging**

- Administration on Aging (AoA) National Family Caregiver Support Program (NFCSP) “Resources Room”
- Family Caregiver Alliance
  [http://www.caregiver.org](http://www.caregiver.org)
- National Alliance for Caregiving
  [http://www.caregiving.org](http://www.caregiving.org)
- National Family Caregivers Association
  [http://www.nfcacares.org](http://www.nfcacares.org)
- Arizona Governor’s Advisory Council on Aging
- Arizona Division of Aging & Adult Services
- Arizona DES Area Agencies on Aging:
- National Institute on Aging
- University of Illinois, Chicago. Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD). See “highlighted topics.”
  [http://www.uic.edu/orgs/rrtcamr/index.html](http://www.uic.edu/orgs/rrtcamr/index.html)
- Arizona Governor’s Council on Developmental Disability
  [http://azgcdd.org](http://azgcdd.org)
  Emergency planning guide: