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Alzheimer's Disease Demonstration Grants to States Program: Oklahoma

Final Report

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**ALZHEIMER'S DISEASE DEMONSTRATION GRANTS TO STATES:
OKLAHOMA**

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EXECUTIVE SUMMARY

The grant for the Oklahoma Alzheimer's Disease Demonstration Grants to States (ADDGS) was selected for a case study to illustrate the issues of systems and sustained change. Oklahoma was chosen because it established innovative programs in the Tulsa, Oklahoma, area that will continue beyond the life of the Grant. While not altering state long-term care policy, the Grant altered the educational system for direct care workers by establishing a Geriatric Technician training program and changed the care environment by establishing an ongoing outreach program for the African American community.

Oklahoma's FY 2002-2005 ADDGS Grant focused on two programs:

- A Geriatric Technician training program at Tulsa Community College, which provides additional training to nursing assistants who have completed a basic level of training (e.g., certified nurse assistants or home health aides). Dementia care is a major focus of the training.
- The Care Connections program at the Alzheimer's Association of Oklahoma and Arkansas, which provides outreach, counseling, and information and referral to persons in need of services and their families, with a focus on African American and rural families. Volunteer respite care is a major component of the services offered.

The main findings of the case study are as follows:

- The Oklahoma Grant contracted with Tulsa Community College and the Alzheimer's Association of Oklahoma and Arkansas to operate the Grant's programs. The activities assigned to each organization were in line with its larger goals. As a result, both organizations valued these activities highly and were committed to continuing the Grant programs at the end of the federal funding.
- Tulsa Community College and the Alzheimer's Association of Oklahoma and Arkansas were relatively large, financially stable organizations, not dependent on Grant funds for their survival. Thus, they could afford to commit resources to the initiatives for the period following the Grant, allowing them to continue. Both organizations were planning fund-raising activities for the period after the grant, largely through local foundations.
- The supply and level of expertise of the direct service workers in long-term care are major problems in the care for people with dementia. The Geriatric Technician program addresses this problem by providing a career ladder for direct service workers, with a strong emphasis on dementia care.
- For a variety of reasons, many minorities are not well integrated into the service delivery system. The Care Connections program is changing the view of Alzheimer's disease in rural and African American communities in the Tulsa area by better connecting persons with services. The faith-based community is a major mechanism for reaching the African American community.

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INTRODUCTION: OVERVIEW OF ADDGS PROGRAM AND CASE STUDIES

Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. A person with late-stage Alzheimer's disease requires constant supervision, support, and hands-on care. While many persons with Alzheimer's disease are admitted to nursing homes, the majority of people with the disease live in the community, where their families provide most of the care.

To improve services to persons with Alzheimer's disease, Congress established the Alzheimer's Disease Demonstration Grants to States (ADDGS) program, which is administered by the U.S. Administration on Aging. The program's mission is to "expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and their caregivers, as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard to reach and underserved people with Alzheimer's disease or related disorders (ADRDs)" (U.S. Administration on Aging, no date).

This paper is one of five case studies conducted by the ADDGS National Resource Center in 2005 on the activities of selected state programs. The goals of the case studies are the following:

- To document "promising practices."
- To identify policy issues relevant to providing services to people with Alzheimer's disease and their families.
- To identify strategies for accomplishing program goals.
- To identify implementation barriers and ways of overcoming them.
- To assess how selected sites are addressing the goals of the ADDGS program.

One of the themes of the case studies is how grantees achieve *systems change* and *sustained change*, which are two of the key priorities of the U.S. Administration on Aging for current and future grantees under the ADDGS program. At its core, these systems and sustained change case studies are about how grantees seek to change the "care environment" for people with Alzheimer's disease and their families. To improve the care environment, it is necessary that:

- The needed services exist and are maintained over time.
- Eligibility criteria for the services include people with dementia and their families.
- People with dementia or their families know that services exist, understand how the services would benefit them, and know how to locate and arrange the services or are effectively assisted with these functions (e.g., through care consultation and information and referral systems and by knowledgeable health, social service, and long-term care providers).

- Service providers are trained and knowledgeable about Alzheimer’s disease and dementia care.
- The quality of the services is high enough that people with dementia and their families will accept and benefit from them.
- Funding is available for the services.

In these case studies, systems change refers to activities that result in ongoing modification in state or local government or provider practices, policies, financing, and delivery of services for people with Alzheimer’s disease and their families. In Maine, for example, the model respite care program established with ADDGS funds and administered by the Area Agencies on Aging was incorporated into the state home- and community-based care system by making respite care a covered service in Medicaid and state-funded programs.

Although often hard to document, an important component of systems change is altering the “ongoing way of doing business” among providers or government officials in ways that take into account the needs of persons with Alzheimer’s disease and their families. An example would be how the North Carolina Grantee established informal relationships among providers and state officials. At the local level, family consultants have developed and trained informal networks of providers to meet caregiver needs. At the state level, the grant leadership is working with officials from a range of departments to coordinate efforts and to develop joint policies to address caregiver concerns. Moreover, some grant activities are supportive of and consistent with overall state efforts at systems change, but they may not alter the financing and delivery system.

Sustained change, on the other hand, refers to whether the activities funded by the project will continue after the grant ends. An example of sustained change is the continued support by Tulsa Community College (TCC) of the ADDGS-initiated Geriatric Technician training program. Sustained change can be achieved through systems change or through obtaining other sources of funding. All systems change is sustained change, but not all sustained change is systems change. Some activities are geared to particular activities or service areas by providers and do not change the overall financing and delivery system within the state.

To illuminate the issues involving systems and sustained change, Maine, North Carolina, and Oklahoma were selected for case studies.¹ Oklahoma was selected for this case study because it established innovative programs in the Tulsa area that will continue beyond the life of the project, or sustained change. While not changing state long-term care policy, the Grant did alter the educational system for direct-service workers and established an ongoing outreach program for the African American community. The two programs that are the focus of the Oklahoma FY 2002-2005 ADDGS program are described in **Exhibit 1**.

¹The other theme of the other case studies is the use of evidence-based practices and the replication of promising practices. ADDGS programs in California and Colorado were selected to illustrate those issues.

Exhibit 1. Principal Components of Oklahoma ADDGS Grant

- A Geriatric Technician training program at TCC, which provides additional training to nursing assistants who have completed a basic level of training (e.g., certified nurse assistants or home health aides). Dementia care is a major focus of the training.
- The Care Connections program at the Alzheimer’s Association of Oklahoma and Arkansas, which provides outreach, counseling, and information and referral to persons in need of services and their families, with a focus on African American and rural families. Volunteer respite care is a major component of the services offered.

Information for this case study was gathered by reviewing administrative files at the U.S. Administration on Aging and on Web sites and by conducting an in-person site visit in August 2005 in Tulsa, Oklahoma. As part of the site visit, RTI staff interviewed ADDGS staff, educators, and representatives of consumer groups, volunteers, and providers.

The principal findings from the Oklahoma case study are listed in **Exhibit 2**.

Exhibit 2. Principal Findings from the Oklahoma Case Study

- To achieve sustainability, the Oklahoma Grant adopted the strategy of contracting with established organizations—TCC and the Alzheimer’s Association of Oklahoma and Arkansas—for which the activities of the Grant were consistent with their ongoing goals and operations. Both organizations see great value in the Grant’s programs and are committed to continuing most of their activities.
- TCC and the Alzheimer’s Association of Oklahoma and Arkansas are financially stable and can afford to commit resources to the initiatives for the period following the Grant. Additional fund-raising activities for the coming year, largely through local foundations, were planned for both components of the grant.
- Addressing the need for a better trained long-term care workforce, the Geriatric Technician program is providing an ongoing mechanism to provide dementia-focused training to direct service workers.
- Addressing the needs of underserved populations, the Care Connections program is changing the view of Alzheimer’s disease in the rural and African American communities in the Tulsa area and better connecting persons with services. Enlisting faith-based communities is a key component of the outreach to the African American population.

BACKGROUND ON OKLAHOMA AND ADDGS GRANTEE

Oklahoma's 3-year ADDGS grant ran from July 1, 2002, to June 30, 2005. The Oklahoma Grant was administered by the Aging Services Division of the Oklahoma Department of Human Services, which is the State Unit on Aging. Within the Aging Services Division, the Grant was administered by the Personal Care Services Unit, which is also coresponsible for Medicaid home- and community-based services waivers for older people and younger people over age 21 with physical disabilities. The ADvantage Medicaid home- and community-based services waiver served approximately 12,000 people with disabilities, about 80 percent of whom were seniors. Nursing home use dropped by about a third over the last 10 years, which state staff linked to the implementation of the waiver. The Personal Care Services Unit also included 125 registered nurses who provided case management for persons receiving nonwaiver personal care services and conducted medical eligibility assessments for waivers, nursing homes, and personal care services. Responsibilities for the Administration on Aging-funded Area Agencies on Aging and the National Family Caregiver Support Program and the state-funded adult day care program were located in other units of the Aging Services Division.

The specific goals of the Grant were:

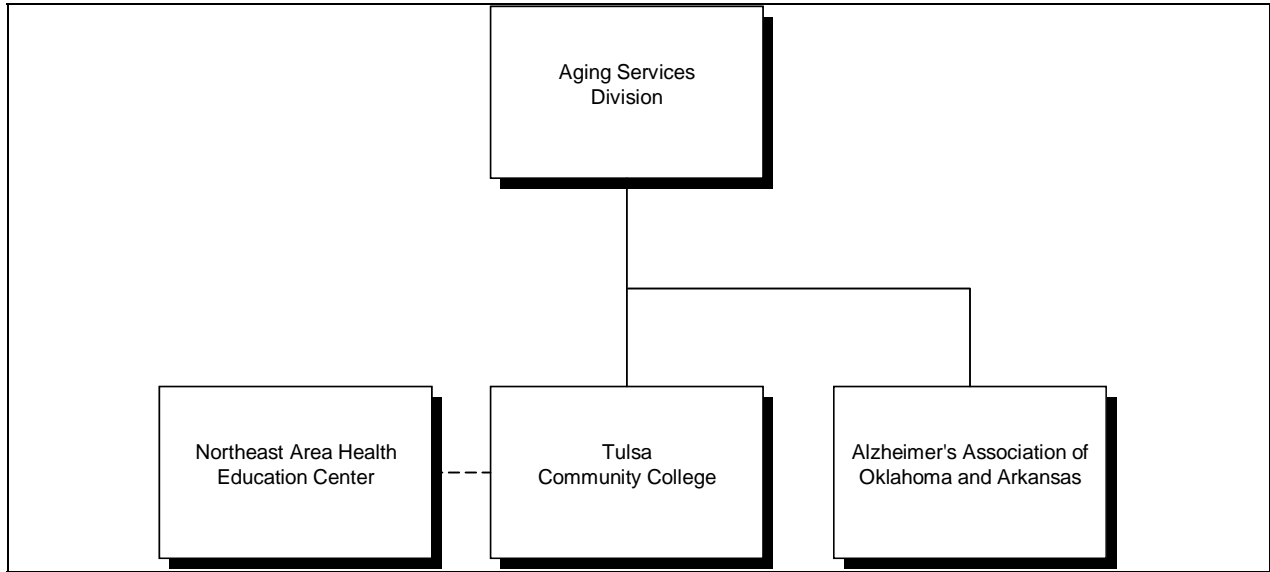
- To develop a training program that provides a career ladder for paraprofessional long-term care workers, with a strong emphasis on dementia care.
- To increase access to direct services for individuals with Alzheimer's disease in the rural and African American communities through care coordination and volunteer visitation programs.

To implement the demonstration initiatives, the Aging Services Division worked with community partner organizations. The most important organizations were:

- TCC, the largest community college in Oklahoma, with approximately 25,000 students on four campuses in the Tulsa area. In addition to the Geriatric Technician program that was supported with Grant funds, its large nursing program offered programs to become a registered nurse, licensed practical nurse, and patient care technician.
- Northeast Area Health Education Center (AHEC), a largely federally funded workforce development and health education center focusing on rural and underserved areas. The AHEC worked with TCC to recruit students for the Geriatric Technician program.
- Alzheimer's Association of Oklahoma and Arkansas, the main advocacy and service organization for persons with Alzheimer's disease in the two states. Tulsa is the administrative headquarters for the chapter, but it also has offices in Oklahoma City, Oklahoma; Fort Smith, Arkansas; Little Rock, Arkansas; Bella Vista, Arkansas; and Fayetteville, Arkansas. The chapter grew substantially over the last 10 years. It offers a wide range of educational and support services, including Care Connections, which was supported by the Grant.

The relationships among the Aging Services Division, TCC, the Northeastern Area AHEC, and the Alzheimer's Association of Oklahoma and Arkansas are shown in **Exhibit 3**.

Exhibit 3. Relationship Among Partners in the Oklahoma ADDGS Grant



GRANT STRATEGIES TO ACHIEVE SYSTEMS AND SUSTAINED CHANGE

The ADDGS Grant worked to improve services for persons with Alzheimer's disease and their families through two main mechanisms.

Establishing a Career Ladder for Long-Term Care Paraprofessionals

Paraprofessional long-term care workers, such as certified nurse assistants, are the backbone of the formal long-term care delivery system, providing the majority of paid assistance to people with disabilities (National Commission on Nursing Workforce for Long-Term Care, 2005; Anderson et al., 2004; Stone and Wiener, 2001). These "frontline" nursing home workers primarily assist with activities of daily living (ADLs, such as eating, bathing, and dressing) and instrumental activities of daily living (such as using the telephone). A major problem confronting long-term care providers is that it is difficult to recruit and retain long-term care workers (Decker, Dollard, and Kraditor, 2001). A key contributor to these problems is that job advancement and growth is very limited. Several states and many providers are exploring new job positions for direct service workers by establishing new job categories, expanding the scope of duties under existing categories, and developing career ladders (Harmuth and Dyson, 2003; Wilson, Eaton, and Kamanu, 2002).

A key premise of the Oklahoma ADDGS program was that increasing training and establishing career ladders were important strategies to help workers develop job competencies and functional skills that would improve their confidence, work satisfaction and, ultimately, job retention. Improved training may also indirectly affect recruitment of workers if better-trained and more satisfied workers improve public opinion of these jobs, making the jobs more attractive to potential recruits.

Background on Oklahoma's Certified Nurse Aide Career Ladder

Training of direct service workers is a long-standing issue in Oklahoma. Starting in the late 1980s, the legislature required that all personal care workers receive 75 hours of training and be certified nurse aides. In 2002, interest in direct service workforce problems in Oklahoma increased when the Continuum of Care Taskforce, a group appointed by the governor and the legislature, recommended the establishment of a "certified nurse aide career ladder model" (Continuum of Care Task Force, 2002). In response to this recommendation and with the help of the ADDGS Grant, the Aging Services Division contracted with TCC to develop a Geriatric Technician program. In addition, although the Grant agency was not involved in its passage, in 2005, the legislature passed a law that required that all certified nursing assistants and home health aides receive at least 10 hours of dementia training. Moreover, to increase the wages of Medicaid personal attendants, the state recently enacted a wage pass-through, requiring that 75 percent of the Medicaid rate increase be spent on salary increases or fringe benefits, which must be documented in a cost report to the Oklahoma Department of Human Services.

Oklahoma has separate training requirements for nursing assistants in long-term care, home health, adult day care, developmental disability, residential care, nursing homes, and assisted living (Continuum of Care Task Force, 2002). It also established a three-level career ladder for paraprofessional long-term care workers. Level I is the basic, entry-level training required for a certified nurse assistant in a nursing home or for a home health aide. Level II

requires 27 hours of additional continuing education in core competencies in such areas as team work and cooperation, quality of life, dementia care, aging and illness, and spirituality and dying. Level III requires a minimum of 30 hours of instruction above Level II in one or more of the following focus areas: Alzheimer's and geriatric care, advanced home care, restorative care, complex care, life skills development for special populations, team leadership and mentoring, or mental health care. The Geriatric Technician program is a Level III training program.

Description of the Geriatric Technician Program

The Geriatric Technician program at TCC provides advanced training on services to older people, with an emphasis on dementia care to certified nurse assistants or other health care workers (TCC, 2003). Students must have already received certification as certified nurse assistants, home health aides, or equivalent positions. TCC does not offer this basic level of training. They must also pass an Oklahoma State Bureau of Investigation criminal background check.

The course lasts 8 weeks and consists of 16 classes, which meet for 8 hours per week (4 hours twice a week), and 16 hours per week of clinical training. Thus, the course includes 192 hours of class time or clinical training, 150 hours of which are on dementia care. At their option, students may break the course into two parts and complete the course over a longer period. This latter approach allows students who have not been in school for awhile or who have difficulty fitting the course into their schedules to complete the training in "smaller bites." As of August 2005, 83 students out of 150 enrollees had graduated.

The program is designed to provide collaborative learning experiences in a variety of long-term care settings, although some graduates work in hospitals. Students receive instruction in the physiological, psychological, and mental aspects of aging, care of individuals with Alzheimer's disease, restorative care, and aging with disabilities. Additional team-building skills emphasize group process, interpersonal communication, and leadership skills. The program focuses on the "whys" of geriatric care to give nursing assistants a deeper understanding of what is being asked of them. Thus, observation and assessments—what to look for and how to know when there is a problem—are key skills that are taught. Geriatric Technicians learn how to assess lung fields, nail beds, and pulses; and the program gives them a way to articulate what they see in medically meaningful ways. The program also provides assertiveness training, which teaches the participants how to make their point without being confrontational.

The dementia care focuses on validation therapy, which emphasizes the emotion behind the behavior. For example, if a person with Alzheimer's disease is carrying a doll and insisting that it is a real baby, the Geriatric Technician validates the emotion by saying, "You must really love babies" rather than trying to convince the person that what they are carrying is not really a baby. The notion is that the person is cherishing the memory of a baby; the doll represents a memory or emotion to the person. In addition, one of the two textbooks is about dementia care.

Students are required to do three process reports with clients. In these reports, students use therapeutic techniques to get to know clients and their families. The program stresses that every communication has a purpose. Through these communication projects, students are better

able to understand what professional staff and clients are doing and to better communicate with them.

As part of the program, students do an in-service project and presentation. One student did an activity at an assisted living facility built around the idea of taking a vacation in Hawaii. The activity included asking trivia questions about Hawaii, giving out prizes, talking about fruits and flowers from Hawaii, decorating the room, and providing refreshments.

Clinical training in TCC's nursing programs usually involves TCC faculty members working directly with students. TCC does not use this approach for its Geriatric Technicians because the school found that students need to be working their shifts and the program cannot afford one-on-one instructors. Instead, they built collaborative relationships with on-site mentors to work with students. The mentor is a licensed practical nurse or registered nurse in a supervisory capacity who is an employee of a nursing facility, home care agency, adult day health program, or hospice. Using mentors also provides a way to have someone at the site encourage the students and make sure that they are following through with their assignments.

Benefits of the Geriatric Technician Program to Students

After successful completion of the Geriatric Technician course, students receive several benefits:

- Graduates receive a certificate as recognition of their completion of advanced training in the care of older people. The program also provides personal recognition for the students' achievements. TCC organizes a graduation party with a cake and a gift, such as a mug with a picture of one of the class activities, and a pen. In addition, certificates are signed by the Oklahoma Department of Human Services as well as school staff. According to the ADDGS project director, it is the Department's way of saying that "DHS recognizes and applauds you." The logos of all of the program's partners are on the certificate to remind them of all of the agencies that supported their effort.
- Graduates receive 6 hours of credit that can be applied to a college degree program. Thus, the program provides an introduction to college for people who might not otherwise consider attending. TCC has a large population of students who have parents with no previous college experience, so the program is working with the first generation of college students.
- Geriatric Technicians can use their courses to meet the prerequisite requirements for admission into the TCC nursing program. Although only a few students have progressed to a higher level of training, the course can be a stepping stone to being a licensed practical nurse or a registered nurse. It is another entry point into advanced education in health care.
- Informal feedback from students, employers, and TCC faculty suggests that graduates feel better about their skills and have greater self-confidence, self-esteem, and sense of adequacy. Graduates report that the training improved their job satisfaction, made

them more confident of their skills and better able to understand the reasons for what they are asked to do, and to feel more a part of a professional care team. One graduate emphasized how much better she could communicate with the licensed nursing staff.

- Although some graduates do receive pay increases and new titles in their jobs after completing the course, this is relatively rare; it is more common in community-based agencies (such as hospices) and hospitals than in nursing homes. This is a major barrier to attracting people to the program. Nursing homes say that they do not have the resources to change how they are hiring and using people. The Oklahoma Medicaid program paid nursing homes on a flat rate basis, so there was a direct trade-off between profits and increased costs. The state was changing to a payment system that varies more with the cost of providing services, which may lessen the disincentive to pay staff higher wages. According to TCC, the business case for the training is that better care is provided, turnover rates are lower, and satisfaction improves, but only limited data and experience are currently available to make the argument.

Barriers and Solutions

In developing and operating the Geriatric Technician program, TCC faced several issues. One difficulty was that many of the students had “life challenges” that created a great deal of stress that impeded their studies. According to the director of the Geriatric Technician program, students tend to be minority single women with young families, who are economically strained, often work two jobs, and do not receive a lot of family support. The program usually has a few students who break down crying, saying that they cannot do the coursework. In response to this problem, the TCC staff does a lot of “hand holding,” including calling these students to remind them about the class and working with them individually to reassure them. The staff invests a lot of time and energy in making sure that the students complete the course.

A second challenge relates to recruiting students. Because the training program is still relatively new and is not required for employment, it does not fit neatly into the existing job structure. As a result, aggressive marketing of the program is required. Enrollment comes from people working in hospices, home health agencies, home care organizations, nursing facilities, and hospitals. Although hospitals were not part of their initial marketing activities, some students who work in acute care facilities enrolled because a high percentage of their patients are elderly. About 75 percent of students work for community-based services. The program draws a wide mix of minorities, including Hispanics, Vietnamese, and Pacific Islanders, but African Americans are the largest group.

Recruitment and outreach take place through one-on-one contact with providers, talking with agency and facility administrators and nursing staff, making presentations at provider in-service trainings, distributing literature at health fairs, advertising in newspapers, and sending mailers to prospective students who call about the program. Increasingly, students also learn about the course by talking with students who have taken the course. To help TCC with recruitment, TCC partners with the Northeast Area Health Education Center.

Some nursing homes are resistant to the new training. In addition to the reimbursement issues discussed above, historically, most nursing homes have trained their own certified nurse assistants and do not see the value of outside education. Moreover, some facilities are afraid that staff will ask for paid time off to attend the class and do not want to be put in the position of having to turn down staff requests or to find additional workers to fill in while students are in class. Most students take the course on their own time or trade shifts with co-workers. Classes are in the evening between 4:00 p.m. and 8:00 p.m., after the day shift.

The cost of the program also presents a barrier to student enrollment. Tuition for the Geriatric Technician program is approximately \$500, including application, lab fees, and criminal background checks, but this cost does not include books. Although the cost is not high in absolute terms, it is a significant sum for this mostly low-income student population. To address this problem, the Grant offered financial aid to about 85 percent of students, and TCC encourages students to apply for federal student financial aid. A few employers pay for part or all of the tuition.

A third challenge relates to transportation to class. Tulsa is a large, spread-out city, without a great deal of public transportation. In addition, some students consider the traffic in Tulsa to be intimidating. One unique aspect of the program is that TCC takes the training to the community rather than requiring everyone to come to the college. Classes are held in a variety of off-campus locations; for example, one course was held at a Department of Veterans' Affairs facility, and another was held at the Owasso Community Center. The goal is to make it more convenient for students to attend.

Sustainability

A key issue is future funding for the program, especially since the current Grant expired on July 30, 2005. The Grant pays for adjunct faculty, a part-time administrative assistant, training materials, textbooks, program marketing, student notebooks, and scholarships for the vast majority of students. The TCC state regents approved the Geriatric Technician program as an ongoing certificate program, and the school will fund the program director and one other full-time staff person. In lieu of using Grant funding for scholarships, the program encourages prospective students to apply for federal student financial aid, but not everyone qualifies. TCC also offers some scholarships on its own. The program is pursuing local foundation support, but it did not have any grants at the time of the site visit.

Care Connections

To meet the Grant's goal of increasing awareness and providing services to underserved populations, the Alzheimer's Association of Oklahoma and Arkansas operates the Care Connections program, which provides outreach, information, and support services to families of persons with Alzheimer's disease in Tulsa, Osage, Creek, and Oklahoma counties (Alzheimer's Association, 2003). A major focus of the program is outreach to African American and rural families. A major innovation of the program is the use of faith-based congregations to reach this community.

The Care Connections program helps families with persons with Alzheimer's disease by:

- Raising awareness about the disease and providing information about diseases that cause memory loss.
- Encouraging members to get help.
- Providing information about community services to help with caregiving and providing help arranging for services.
- Hosting education programs.
- Providing volunteer and some paid respite care, through individual volunteer and team models.
- Identifying volunteers to support caregiving families.

For Medicaid-eligible persons with Alzheimer's disease and families seeking National Family Caregiver Support Program-funded respite care, a major goal of the program is to provide gap-filling services until publicly funded services can be provided. On average, it takes 6 weeks from application to the start of Medicaid-funded services. An expedited eligibility determination is available if there is an emergency. In addition, demand for respite care through the National Family Caregiver Support Program is very great, resulting in a long waiting list. For that program, it can take 3 to 4 months before an approval is obtained.

Care Consultation and Volunteer Respite

Key components of the services available are care consultation and volunteer respite care.

Care Consultation. The professional care consultant assists families in accessing support services and planning for the future. The care consultant often meets with families who need help after a diagnosis and know they need to do something but are not sure what to do. It is often hard for families to accept the reality of having a relative with dementia and what it means for the individual and the family. For other families, the diagnosis becomes a way of making sense of what seemed to be bizarre behavior. Some families are in crisis and need help quickly.

The care consultant does a family assessment, which covers the care situation, gaps in knowledge, establishment of Power of Attorney and advance directives, and possible eligibility for Medicaid and other public programs. If there is family conflict, the care consultant works to resolve it. The care consultant stresses the need for caregivers to take care of themselves in addition to the person with Alzheimer's disease. The staff also provides information about the disease itself and how important it is to respond to what the person with the disease is experiencing at that moment. Basic information about the stages of the disease, what to expect, difficult behaviors, and effective communication strategies are also provided. If ongoing services are needed or desired, help is provided in arranging for them.

Volunteer Respite. Care Connections also recruits volunteers to provide in-home volunteer respite, including taking care of errands, calling to check-in on the family, visiting on a

regular basis, or other kinds of help requested by the families. Many volunteers become involved because of their experience caring for a deceased relative. A major goal of the program is to let caregivers know that they are not alone and that there is some help available. One of the Association's messages is that the volunteer benefits as well as the person receiving the respite care. The philosophy is that giving of yourself makes the world a better place. In some cases, the volunteers make tremendous personal investments and sacrifices. In one case, a volunteer arranged for Habitat for Humanity to build a house for a family and helped to build it; she also bought groceries with her own money.

Volunteers receive 3 to 4 hours of training about the disease, what they can and cannot do (e.g., they cannot provide hands-on personal care or do household chores), confidentiality, where to send reports, and how to interact with the family and the person with Alzheimer's disease. On their "sharing the caring" form, the Association gathers information about the family situation, such as what the person with Alzheimer's disease likes to eat, the names of any pets, and other items that help the volunteer interact with the family and the person with Alzheimer's disease. To help sustain the volunteers and to improve the services provided, experienced care mentors work with new volunteers, especially on how to cope with disruptive behaviors.

Challenges in operating the program include recruiting volunteers and successfully matching volunteers and families. An ongoing problem is that a substantial number of volunteers end up not providing services. One possible reason is fear of people with Alzheimer's disease, which the program tries to address by providing information and training volunteers in how to interact with persons with dementia.

Beyond willingness to actually provide help, it is often difficult to match families and volunteers because of work schedules, geographic locations, ethnic preferences, and personalities. In general, very few people are willing to travel very far to volunteer. One strategy that proved successful was to throw a party for caregivers and families, which provides an opportunity for large numbers of people to meet one another and find a match. For all matches, volunteers and families have a preliminary visit to get acquainted and decide if the fit is good.

To help increase the number of volunteers participating in the program, the Grant created "care teams" so that an individual volunteer would not be alone in supporting a family. Care teams are a group of volunteers who work together to support a family. The program staff believes that the care teams are effective in overcoming volunteer reluctance to participate and help maintain involvement over time. In the teams, each individual usually has a smaller time commitment and provides support to other team members. For example, one volunteer might check in with the family on a regular basis to see how they are doing, another volunteer might do errands that need to be done, and still another might provide respite for the caregiver. In other circumstances, team members might rotate providing respite care, each going once a month. One of the volunteers acts as "captain" of the care team and is the liaison with the Alzheimer's Association and other team members. A potential trade-off is that this approach may end up serving fewer persons because each family is using more volunteers, but that effect may be offset if volunteers serve for longer periods of time.

Evaluation. The Alzheimer's Association conducted surveys of service users, which found high levels of satisfaction. However, the surveys had very low response rates, only about 5

percent, casting doubt on their validity. In addition, as part of the original study of the ADDGS program, the ADDGS Evaluation Team at the University of Wisconsin-Milwaukee collected descriptive data in 2003 on respite service users, although the Oklahoma sample was very small (32 respondents) and, thus, could not be analyzed separately (ADDGS Evaluation Team, 2003).

Possible Alteration of State Policy. One lesson from the ADDGS program is that people with Alzheimer's disease need a lot of supervision but not necessarily a lot of hands-on care. For the Medicaid program, this is problematic because the personal care benefit requires that the personal care assistant provide hands-on help with ADLs. The Project Director was planning to review the service definition to better accommodate the needs of people with Alzheimer's disease. In addition, she was trying to connect the volunteers in the Care Connections program with the state volunteer credit bank initiative, in which volunteers earn "credits" that can be used for volunteer services if they need them in the future.

Minority Outreach

Tulsa and the surrounding counties have substantial African American populations, which have not been well integrated into the Alzheimer's disease service system. According to Grant-funded staff, Alzheimer's disease is not talked about within the African American community; the families of persons with Alzheimer's disease often keep it a secret from other members of the community and the faith congregation. Others are afraid of finding out that a loved one has the disease. According to Tulsa observers, the approach of the African American culture is to "take care of your own" and not to ask for help, even when the demands of doing so are overwhelming. A related problem is that the African American community does not know about available resources and services are limited. Finally, a lack of trust of the larger community by the African American community and the fear of intrusion by government and private agencies compound the problem. Many African Americans believe receiving services through Care Connection is the same as accepting welfare and will adversely affect their privacy and dignity.

The premise of the Grant was that the best way to reach the African American community was through faith-based communities. To facilitate work in the African American community, the Alzheimer's Association hired a family counselor in Tulsa who also manages the woman's ministry of a large church. The family counselor is working with other ministers in the community to inform people about Alzheimer's disease and to publicize the help available from the project. The family counselor visits homes of potential clients to conduct preliminary needs assessments, connect families with information and services, and schedule families for volunteer respite services.

As a way of finding families in need of services, the family counselor contacted pastors to ask if she could make presentations at their churches. She also held a variety of events, including town hall meetings and legal seminars, to educate people about Alzheimer's disease and to identify families coping with the disease. The events were advertised in the newspaper and community newsletters, through mass mailings and announcements made in the churches, and through hand-delivered letters to the community churches. The family counselor made in-person contacts with pastors at over 200 churches to encourage them to announce the events during their services. Many pastors reported not knowing that their parishioners had Alzheimer's

disease; they thought that they no longer attended services because they had lost interest in the church. The program encourages pastors to be more actively involved in meeting the needs of these families. The care coordinator is also responsible for recruiting and training volunteers and matching them with caregivers.

One of the most successful events was the “Maintain Your Brain: An African America Event” in Greenwood. To attract attendees, the program was a combination of entertainment, educational sessions, and a silent auction. Sponsors ranged from individuals to churches to health clinics to the Oklahoma Jazz Hall of Fame. Pastors of 30 different churches were asked to send 10 members of their congregation to attend the education session. A total of 450 persons attended.

The project also developed an educational brochure targeting African Americans, which provided a definition of Alzheimer’s disease, the 10 warning signs of Alzheimer’s disease, how African Americans may be at elevated risk because of their prevalence of high blood pressure, and how African Americans play a role in the Alzheimer’s Association. The brochure also promotes the concept that while “taking care of your own” is a family value, caregivers often need assistance and there is nothing wrong with accepting help.

Rural Outreach

In addition to the African American community, a major focus of Care Connections is rural communities, especially in Osage and Creek counties, where a family counselor conducts outreach and provides care consultation. Family counselors also link their communities with the Alzheimer’s Association Chapter volunteer visitor program.

There are a number of barriers to reaching persons in rural communities. First, the independence of the residents can be a barrier to use of services. According to Alzheimer’s Association staff, rural people have an “I can take care of myself” spirit, which is often counterproductive when caring for someone with Alzheimer’s disease. Second, small town residents are resistant to outsiders offering advice. As one Alzheimer’s Association staff person put it, “rural people in Oklahoma are not crazy about people from Tulsa telling them what to do.” Third, there is a stigma and lack of awareness about the disease. For example, at one health fair, people seemed to actively avoid the Alzheimer’s Association representative reportedly because they feared that they or someone in their family would be labeled as having the disease.

Some strategies that the program used to overcome these barriers include:

- Having people in the community endorse the Care Connections program and the volunteer services it provides. For example, one of the mayors in Osage County proclaimed an Alzheimer’s disease awareness day.
- Meeting people on their own turf. For example, once a month, the care consultant meets a group of local residents in the back of a grocery store where they have lunch.
- Working with advocates for older people, attending health fairs, and holding awareness meetings.

- Establishing contact with the police departments, especially providing them with information about how to cope with persons with Alzheimer's disease.

Sustainability

Because the Oklahoma ADDGS program did not receive an award for the period beginning July 1, 2005, the Alzheimer's Association must find alternate funding sources for Care Connections. For the most part, the Alzheimer's Association is absorbing this project into its ongoing operations and will use its own funds to sustain the project. The project underscored the needs of the African American and rural communities, which the Board of the Alzheimer's Association sees as a top priority for programming and fund-raising.

CONCLUSIONS

The Oklahoma ADDGS Grant had two main components: the Geriatric Technician program at TCC and the Care Connections program operated by the Alzheimer's Association of Oklahoma and Arkansas. The Geriatric Technician program provides advanced training to certified nurse assistants, home health aides, and other paraprofessional workers on caring for older people, especially persons with dementia. The Care Connections program provides outreach, care consultation, and services (including volunteer respite care) to the African American and rural communities.

Key lessons from the Geriatric Technician program are:

- Additional paraprofessional training is important for self-confidence, competence, and improved quality of care, but it is very difficult to translate into salary increases or new positions for workers.
- Advanced training can provide college credit to people who would not otherwise consider college and can be a portal into more advanced training programs to become a licensed practical nurse or a registered nurse.
- Since advanced training of direct service workers does not fit neatly into existing staffing programs or requirements, aggressive one-on-one marketing is needed, at least at the beginning.
- Many students had challenging home and work environments, which make completing classes difficult. Many students require substantial "hand holding."
- Although the \$500 tuition was not high in absolute terms, it is a barrier for many of the students. The Grant was able to subsidize the vast majority of students.
- Transportation is a barrier for many students. The program addresses this issue by offering classes in the community as well as at the campuses.

Key lessons from the Care Connection program are:

- Because of differences in schedules, personalities, geographic locations, and other factors, linking volunteers and families can be difficult and time consuming. In addition, fear of the behavior of people with Alzheimer's disease may prevent some volunteers from following through and donating their time. Training and using volunteer mentors and care teams can help sustain volunteers.
- Outreach through the faith-based community is a good way to develop relationships with the African American community. However, most pastors are not well versed in Alzheimer's disease or on its impact on their congregations. Involving pastors requires a lot of one-on-one marketing.

- Both the African American and rural communities are highly independent and have cultures that emphasize taking care of family members on their own. Education is needed to convince families that outside support is acceptable and available.

Especially since Oklahoma did not receive a follow-on grant to support its activities, sustainability is a major issue for the programs it established. To achieve sustainability, the Oklahoma Grant adopted the strategy of contracting with established organizations—TCC and the Alzheimer’s Association of Oklahoma and Arkansas—for which the activities of the Grant were consistent with their ongoing goals and operations.

In terms of systems change at the state level, the Grant did not have any direct effect on Medicaid or other long-term care policies, although there may be some impact in the future. For example, the project director, who also has responsibility for policy development for the personal care program, was committed to considering revisions of the personal care benefit under Medicaid to make respite a covered activity for a targeted population.

In terms of more general sustained change, however, the Grant sponsored programs that will continue in the Tulsa area after the grant ends. Addressing the need for a better trained long-term care workforce, the Geriatric Technician program is providing an ongoing mechanism to provide dementia-focused training to direct service workers. Similarly, the Care Connections program may be permanently changing the view of Alzheimer’s disease in the rural and African American communities in the Tulsa area and better connecting persons with services. Both of these programs offer models for other communities. Both of these initiatives have influenced the care environment of people with Alzheimer’s disease and their families.

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