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Implementing Systems and Sustained Change in Long-Term Care: The Experience of Alzheimer's Disease Demonstration Grants to States (ADDGS) Programs

Executive Summary

Prepared for

Lori Stalbaum, M.S.W.
Administration on Aging
1 Massachusetts Avenue, NW
Washington, DC 20001

Prepared by

Joshua M. Wiener, Ph.D.
David Brown, M.A.
Deborah Osber, M.A.
Nancy Mitchell, B.A.
Kristin Siebenaler, M.P.A.
RTI International
Health, Social, and Economics Research
1615 M Street, NW, Suite 740
Washington, DC 20036

RTI Project Number 0209351.000.008

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Joshua M. Wiener, Ph.D.
David Brown, M.A.
Deborah Osber, M.P.H.
Nancy Mitchell, B.A.
Kristin Siebenaler, M.P.A.

AoA Project Officer: Lori Stalbaum, M.S.W.

RTI International[*]

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The ADDGS Program

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).

Purpose of Case Studies

The purpose of these case studies is to provide information to states, consumers, and providers on how U.S. Administration on Aging's ADDGS programs in Maine, North Carolina, and Oklahoma achieved systems change in their long-term care systems (Brown, Siebenaler and Wiener, 2006; Osber and Wiener, 2006; and Wiener and Mitchell, 2006). The case studies:

- Document "promising practices."
- Identify policy issues in providing services to people with Alzheimer's disease and their families.
- Identify implementation barriers and ways of overcoming them.
- Assess how selected sites are addressing the goals of the ADDGS program.
- Provide examples of how the ADDGS Grants improve the long-term care system for people with Alzheimer's disease, which is a key goal of the U.S. Administration on Aging.

What Is Systems and Sustained Change?

The theme of these case studies is how ADDGS 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 ADDGS programs. 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 and supports exist beyond the federal funding period.
- Eligibility criteria for the services and supports 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 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 consider the needs of persons with Alzheimer's disease and their families. For example, North Carolina and California established informal relationships among providers and state officials that have added dementia concerns to the formation of long-term care services and policy. Some Grant activities are supportive of and consistent with overall state efforts at systems change but may not themselves 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 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 efforts are geared to particular activities by providers that do not change the overall financing and delivery system.

Methodology

Programs in three states— Maine, North Carolina, and Oklahoma—were chosen for case studies because they had changed the long-term care system in their states or had established programs that were sustained beyond the life of the project. Information for this case study was gathered by reviewing administrative files at the U.S. Administration on Aging and various Web sites and by conducting in-person site visits in the three states in June through August 2005. As part of the site visit, RTI staff interviewed ADDGS staff, educators, researchers, representatives of consumer groups, volunteers, and providers.

Overview of Programs in Maine, North Carolina, and Oklahoma

Maine: The Maine ADDGS project is administered collaboratively by the Bureau of Elder and Adult Services (the State Unit on Aging) and the Muskie School of Public Service at the University of Southern Maine. Maine's ADDGS Grant activities began in 1992 with a focus on improving the state's capacity to respond to the needs of persons with Alzheimer's disease and their families and to promote systems development. In part, this goal was accomplished by establishing a statewide paid respite program, which was modeled on the ADDGS respite program. Grant staff actively participated in state initiatives to expand home- and community-based services, while protecting the interests of persons with dementia. During the shift toward greater home- and community-based services that began in 1996 and continues today, Grant staff provided expertise to the state and the Area Agencies on Aging on Alzheimer's disease and dementia care, which was used in redesigning the state assessment form and nursing facility level-of-care criteria. The major activities of the FY 2004–2007 Grant are expanding services for caregivers in rural areas by adding mental health, end-of-life care, and hospice referral services; expanding the focus of single points of entry to long-term care to include family caregivers and end-of-life care; and enhancing dementia training for the direct-service workforce through the Best Friends training program.

North Carolina: North Carolina ADDGS Grant activities began in 1992 with a project to establish respite centers in underserved low-income, rural, and minority areas of the state. Since 2001, the state has been using ADDGS Grant support to implement Project C.A.R.E. (Caregiver Alternatives to Running on Empty) through a partnership among the Division of Aging and Adult Services in the North Carolina Department of Health and Human Services, the Duke University Center on Aging Family Support Program, the Western North Carolina Chapter of the Alzheimer's Association, several Area Agencies on Aging, and the Mecklenburg County Department of Social Services. Project C.A.R.E. is providing integrated access to information and services to underserved low-income, rural, and minority families by using Family Consultants who are trained in dementia care and supported by dementia and social work experts. These Family Consultants provide caregivers with personalized support through in-home assessments and care planning, respite funding with a wide degree of flexibility and choice, and education and training. Project C.A.R.E. is also increasing the availability of services as the Family Consultants develop networks of provider agencies that bring high-quality, dementia-specific respite services to caregivers, as well as creating networks of governmental and volunteer agencies to jointly serve dementia caregivers. Project C.A.R.E. is demonstrating that the program can be administered under the direction of different entities, a nonprofit organization like the Alzheimer's Association and a county Department of Social Services, allowing the program to be tailored to local and regional circumstances.

Oklahoma: The Oklahoma ADDGS Grant focused on providing services in the local Tulsa area, rather than at the state level. The Grant had two main components, which have continued after the Grant ended: the Geriatric Technician program at Tulsa Community College and the Care Connections program operated by the Alzheimer's Association of Oklahoma and Arkansas. The Geriatric Technician program provides advanced training on caring for older people, especially persons with dementia, to certified nurse assistants, home health aides, and other paraprofessional workers. The Care Connections program provides outreach, care consultation, and services (including volunteer respite care) to the African American and rural communities. A unique aspect of the program is its use of the faith-based community to educate minorities about Alzheimer's disease and to identify persons in need of services.

Strategies and Tactics for Reform

Maine, North Carolina, and Oklahoma used a variety of strategies and tactics to achieve systems change to their long-term care system and to sustain their initiatives. These approaches can be adopted by other states, consumers, or providers to make their long-term care systems more responsive to people with Alzheimer's disease. These strategies and tactics included:

- *Integrating the needs of family caregivers and people with Alzheimer's disease into public programs and long-term care planning.* All of the states sought to change the conceptual framework of long-term care programs to take into account the needs of caregivers as well as individuals with disabilities. Since most states focus exclusively on the person with disabilities, this represents a major paradigm shift in how long-term care services are organized and financed. In Maine, the Grant helped redefine Medicaid nursing home eligibility criteria to better account for the needs of persons with Alzheimer's disease. As a result of work by Project C.A.R.E. in North Carolina, the state made a commitment to provide integrated services to dementia caregivers. In Oklahoma, the state was considering redefining the Medicaid personal care benefit to include respite care.

- *Building Alzheimer's disease technical expertise at the state, Area Agency on Aging, and consumer and provider levels.* The Grants consistently sought ways to increase knowledge about Alzheimer's disease among policy makers and providers. Thus, the Maine Project Director was consulted on state policies, such as revising the assessment form for publicly funded services, which had a major impact on access to services by persons with Alzheimer's disease and their families. In Oklahoma, the ADDGS Project Director was also responsible for the Medicaid home- and community-based services waiver, allowing her to integrate what she learned about Alzheimer's disease into the broader system.

- *Operating demonstration projects that could be implemented statewide.* When states decide to rebalance their long-term care systems, they must decide on what services to expand. By operating innovative demonstration projects, the ADDGS programs offered states a menu of possible options. For example, from the beginning, the Maine Grant funded respite care through a variety of models. As a result, when state long-term care policy shifted to expanding home- and community-based services, the ADDGS respite care service was an ongoing service model that the state could readily adopt. The state now operates its own state-funded respite program and covers respite services as part of its Medicaid home- and community-based services waiver. While some of this success reflects "being at the right place at the right time," it is also a product of having an innovative product that can be replicated on a statewide basis.

- *Linking people with Alzheimer's disease and their families to existing services.* Services specific to people with Alzheimer's disease and their families are a small part of the long-term care and health care system and a small part of the services used by this population. A major focus of all three Grants was linking people with the larger care system. Thus, in Maine, the goal of the hospice initiative is to increase use of the already established Medicare- and Medicaid-funded hospice benefits. In North Carolina, state officials believe that the personalized one-on-one intervention provided by Family Consultants established trust with hard-to-reach low-income, rural, and minority populations, which have not historically sought dementia-specific respite services. The Family Consultants are valuable in presenting the respite options through in-home assessments and by linking families with other long-term care services. In Oklahoma, outreach through the faith-based community was an innovative way to develop relationships with the African American community and link people to services. Once these linkages are established, grantees believe that they will be institutionalized as the normal way of "doing business."

- *Increasing access and availability of a comprehensive range and type of dementia-specific services.* One of the main accomplishments of the Grants, often at the local level, was to broaden the options available to caregivers and people with Alzheimer's disease. As part of the goal of creating a comprehensive range of services, Project C.A.R.E. in North Carolina is committed to flexibility in meeting the caregiver's needs, in terms of both the individualized attention provided by the in-home assessment and the respite options available for caregivers. At the state level, Project C.A.R.E. works with other agencies and grants to expand consumer-directed services and to increase the availability of adult day care.

- *Establishing ongoing training programs.* One of the major activities of the Grants was to provide training to providers and families. By providing this training, the Grants sought to improve the care provided to persons with Alzheimer's disease. In Maine, the grant took the already established and tested Best Friend training for Alzheimer's disease services and institutionalized it as a regular training program. The strong positive response of providers to the training resulted in large numbers of staff being taught the tools to better provide services to persons with Alzheimer's disease. As with all training in long-term care, high turnover rates mean that persons receiving the training do not necessarily stay within the field. This problem was addressed by also giving the training to higher level administrators who have lower turnover rates and by establishing an ongoing relationship with facilities and agencies receiving the training. In Oklahoma, the Geriatric Technician program at Tulsa Community College provides advanced training to certified nurse assistants or other health care workers on services to older people, with an emphasis on dementia care.

- *Embedding initiatives in larger organizations and ongoing activities.* In several initiatives in Maine, the Grant funded only part of the salary of a staff member who worked for a large organization. Doing so increased the likelihood that money could be "found" to support the individual and the activity once Grant support ended. Similarly, the Oklahoma grant adopted the strategy of contracting with established organizations—Tulsa Community College and the Alzheimer's Association of Oklahoma and Arkansas—for whom the Grant activities were consistent with their ongoing goals and operations. Both organizations saw great value in the Grant's programs and are committed to continuing most of its activities. Importantly, both organizations have the funds to continue funding most of the staff and programs established by the Grant.

- *Funding research to evaluate Grant-funded activities and partnering with colleges and universities to provide technical assistance and training.* Institutions of higher learning have research and substantive expertise that were tapped to conduct evaluations and trainings. To systematically document the benefits of some of its initiatives, such as the Maine Caregiver Companion Program, the Grant funded research to evaluate the effectiveness of its services and initiatives. This activity was based on the notion that services showing quantifiable benefits will generate more government funding support. The Duke University Center on Aging Family Support Program is a critical component of the North Carolina program, providing important substantive expertise on addressing the needs of caregivers. In Oklahoma, the program partnered with Tulsa Community College to establish a program of advanced training for certified nurse assistants.

The ADDGS programs in Maine, North Carolina, and Oklahoma used their Grants to create systems and sustained changes in their state long-term care systems, improving services and financing for caregivers and persons with Alzheimer’s disease. A high priority for the U.S. Administration on Aging is to ensure that enduring changes occur as a result of these Grants. The individual case studies present additional information that other states can use on how these three states accomplished these changes.

Further Information

The full case studies are available at http://www.aoa.gov/alz. For further information, please contact Joshua M. Wiener, Ph.D., Co-Director of the Alzheimer’s Disease Demonstration Grants to States National Resource Center, at (202) 728-2094 or jwiener@rti.org or Diane Braunstein, Technical Assistance Director of the Alzheimer’s Disease Demonstration Grants to States National Resource Center at (202) 638-8664 or diane.braunstein@alz.org. For information about the U.S. Administration on Aging’s Alzheimer’s Disease Demonstration Grants to States (ADDGS) program, please contact Lori Stalbaum, ADDGS Project Officer, at (202) 357-3452 or lori.stalbaum@aoa.hhs.gov.

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