January 2006

Alzheimer's Disease Demonstration Grants to States Program: Maine

Final Report

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ALZHEIMER'S DISEASE DEMONSTRATION GRANTS TO STATES: MAINE

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Contract No. GS-10F-009L MOBIS
Delivery Order No. HHSP233200400143U

January 2006

This project was funded by the Administration on Aging under contract no. GS-10F-0097L MOBIS, Delivery Order No. HHSP233L00400143U. The statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Administration on Aging or RTI International. RTI assumes responsibility for the accuracy and completeness of the information contained in this report. The authors would like to thank the ADDGS Grant staff, other state officials, providers, consumers, researchers, educators and others who gave so generously of their time to provide information about Grant activities.

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*RTI International is a trade name of Research Triangle Institute.

EXECUTIVE SUMMARY

The Alzheimer's Disease Demonstration Grant to Maine is administered collaboratively by the Bureau of Elder and Adult Services, which is the State Unit on Aging, and the Muskie School of Public Service at the University of Southern Maine. The primary community partners include the Area Agencies on Aging, the Maine Alzheimer's Association, Maine's National Family Caregiver Support Program, Goold Health Services, and Elder Independence of Maine. Goold Health Services is responsible for assessing and determining eligibility for all long-term care. Elder Independence of Maine provides care coordination and case management to all long-term care programs. Additionally, the agency administers the Caregiver Companion Program; this program provides support to caregivers of individuals with Alzheimer's disease.

Maine has received Alzheimer's Disease Demonstration Grants to States (ADDGS) funding continuously since 1992. Each Grant award built on the previous Grants' successes and expanded the continuum of care available to individuals with Alzheimer's disease and their caregivers.

To achieve systems and sustained change, the Maine ADDGS program used a number of strategies, including:

- Designing and operating projects that can be implemented statewide.
- Linking people with Alzheimer's disease and their families to existing services.
- Building Alzheimer's disease technical expertise at the state, Area Agencies on Aging, and consumer levels.
- Establishing ongoing training programs using already existing established curriculum.
- Embedding initiatives in larger organizations and ongoing activities.
- Investing in funding research to demonstrate the value of Grant-funded activities.
- Leveraging ADDGS funding where possible.

In sum, over its 13 years of operation, the Maine ADDGS program was involved in a large number of initiatives that ranged from early diagnosis to end-of-life care. Through a variety of strategies, the Grant has changed the financing and delivery system for people with Alzheimer's disease and their families in the state of Maine.

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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 discusses 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 related to 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] Maine was selected for this case study because it has institutionalized many of its innovations into the long-term care and medical care systems in the state. As a rural state, Maine faces problems associated with a lack of providers and the great distances people with Alzheimer’s disease and their families must travel to reach urban centers that have expertise in providing services to this population. To achieve systems change, Maine used a wide variety of strategies.

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

Information for this case study was gathered by reviewing administrative files at the Administration on Aging and Web sites and by conducting an in-person site visit in June 2005 in Augusta and Portland, Maine. As part of the site visit, RTI staff interviewed ADDGS staff, state officials, research experts, providers, and consumer groups.

The principal findings from the Maine case study are listed in **Exhibit 1**.

Exhibit 1. Principal Findings from the Maine Case Study

To achieve systems and sustained change, the Maine ADDGS Grant program used a number of strategies, including:

- Designing and operating projects that can be implemented statewide.
- Linking people with Alzheimer's disease and their families to existing services.
- Building Alzheimer's disease technical experts at the state, Area Agencies on Aging, and consumer levels.
- Establishing ongoing training programs using already existing established curriculum.
- Embedding initiatives in larger organizations and ongoing activities.
- Investing in funding research to demonstrate the value of Grant-funded activities.
- Leveraging ADDGS funding where possible.

BACKGROUND ON MAINE AND ADDGS GRANTEE

Maine was one of the original 15 grantees of the ADDGS program and has received funding continuously since 1992. The Maine ADDGS project is administered collaboratively by the Bureau of Elder and Adult Services,[2] which is the State Unit on Aging, and the Muskie School of Public Service at the University of Southern Maine. The state and the university have collaborated on policy analyses, research and demonstration projects, and program evaluations since the 1980s.

As the State Unit on Aging, the Bureau of Elder and Adult Services works to establish the overall plan, policy objectives, and priorities for services for Maine's older persons. It includes a unit for community programs, which manages Older Americans Act services (including the National Family Caregiver Support Program); the Aging and Disability Resource Center Grant; and a unit on long-term care programs, which oversees Medicaid long-term care services (including two Medicaid home and community-based services waivers—one for services for the elderly and one for adults with disabilities) and state-funded home care programs. As shown in **Exhibit 2**, a number of persons receiving publicly funded home- and community-based services in Maine have Alzheimer's disease or another dementia. In addition to managing access to the public long-term care benefits, the Bureau of Elder and Adult Services is responsible for determining medical and functional nursing home eligibility (regardless of payer) and for developing and licensing congregate housing facilities.

Exhibit 2. Percentage of Persons Using Maine's Long-Term Care System with a Diagnosis of Dementia, 2004

Service	Percentage
Nursing facilities	50
Community services	15
All services	34
Private duty nursing—Medicaid	11
Home-based bare (state funds)	11
Medicaid waiver for the elderly	35

Source: Bureau of Elder and Adult Services, 2005.

The initial award of the Grant preceded a major policy shift on long-term care in Maine. In 1996, the state adopted a strategy to reduce reliance on institutional long-term care and to expand home and community-based service choices for individuals and their families. A major component of the state strategy to reduce nursing home use was to substantially tighten and medicalize the level-of-care requirements, a change that heavily affected persons with Alzheimer's disease as they lacked a skilled nursing need. The level-of-care requirements were determined by a universal screening tool used for all home- and community-based and nursing

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[2] On October 1, 2005, the name of the State Unit on Aging, the Bureau of Elder and Adult Services, was changed to the Office of Elder Services.

home care services. Critics argued that the necessary home- and community-based services, especially residential alternatives, did not exist yet, leaving persons with Alzheimer's disease without viable service options. State officials argued that equity required eligibility criteria and services that were not limited to or tailored for specific groups of persons with disabilities.

The Maine Alzheimer's Association was among the critics and believed that the newly implemented universal screening tool negatively affected persons with Alzheimer's disease. To force a change in policy, the Alzheimer's Association went to the legislature and appealed for a change in the eligibility requirements. The legislature directed the Bureau of Elder and Adult Services to create a team of stakeholders to find a solution to the conflict. As part of the problem's resolution, the assessment instrument was changed to include a cognitive and behavioral component reflecting Alzheimer's disease impairments. The ADDGS Project Director was a member of the stakeholders group that created the tool. An additional result of the legislative appeal was to implement respite services based on the ADDGS model across the state, increase funding for home- and community-based services, support residential alternatives, and raise funding for the training of staff working with people with dementia.

To implement the demonstration initiatives, the Bureau of Elder and Adult Services works with community partners. Since 1992, the primary Grant partners have included:

- **Goold Health Services,** which assesses and determines eligibility for all long-term care clients for nursing home- and community-based services, regardless of payer source.

- **Elder Independence of Maine,** which provides care coordination and case management to all long-term care consumers receiving publicly funded community-based long-term care programs. This agency also administers the Caregiver Companion Program; the program that provides support to caregivers of persons with Alzheimer's disease.

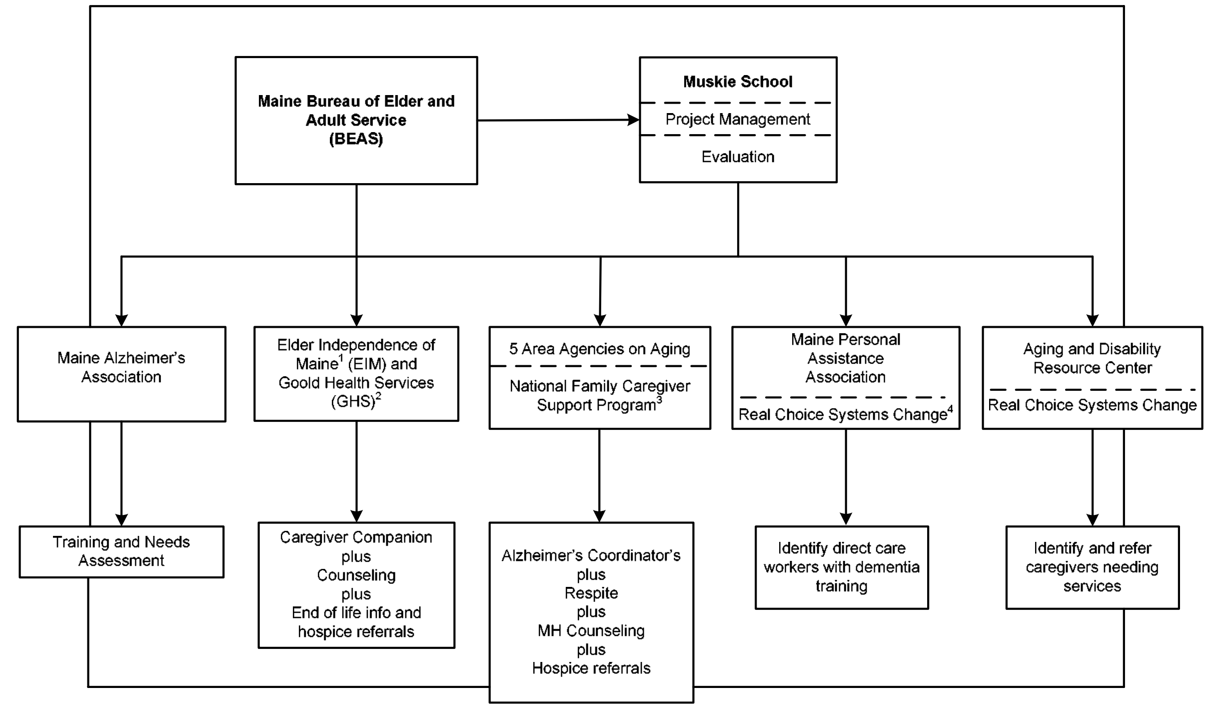
- **Area Agencies on Aging,** which provide services and advocacy for older people. The goal of the five Area Agencies on Aging is to ensure that seniors and their caregivers receive services to allow them to remain in the community and maintain the highest level of independence. Through Older Americans Act funding, the ADDGS Grant, and other state and federal funds, Area Agencies on Aging provide information and assistance, individual counseling, support groups, caregiver training, respite care, mental health services for caregivers, and referrals to hospice services.

- **Maine Alzheimer's Association,** which has provided a range of services and training to Maine residents because of the availability of Grant funding. For people with Alzheimer's disease and their families, the Association provides information and referral services.

- **Maine's National Family Caregiver Support Program,** which administers the U.S. Administration on Aging program for caregivers in Maine. The ADDGS Grant collaborates closely with the National Family Caregiver Support Program, particularly through the respite programs. Both programs are administered through the Area Agencies on Aging, and the program staff are either in the same unit or responsible for both programs. The two programs work together to ensure caregivers are receiving services through the proper venue and will often refer to the other program.

The relationship between the state, the Muskie School and its partner organizations is shown in **Exhibit 3**.

Exhibit 3. Maine Alzheimer's Demonstration Project Partners, FY 2004–2007



[1] EIM is the single statewide agency for coordinating home and community based services for BEAS
[2] GHS is the single statewide agency for overseeing people's need to eligibility for LTC
[3] Each of the 5 AAAs coordinate the National Family Caregiver Support Program
[4] Maine Personal Assistance Association was started under Real Choice Systems Change grant (2001-2004) and further supported under Direct Service Workforce Grant (2003)

Source: Maine ADDGS Grant Application, 2004.

GRANT STRATEGIES AND ACTIVITIES TO ACHIEVE SYSTEMS AND SUSTAINED CHANGE

The Maine ADDGS Grant works for systems change through a variety of mechanisms.

Providing Expertise to State and Area Agencies on Aging on Alzheimer's Disease and Dementia Care

Because of the availability of Grant funds and the interest in combining Grant services with state services, issues relating to Alzheimer's disease received a place at the "policy table." With this money came the Alzheimer's disease expertise of the Grant staff who provided a voice for the special service needs of people with Alzheimer's disease and the family members who care for them. The Grant Project Director saw part of her role as an advocate for these individuals.

Alzheimer's Coordinators at the Area Agencies on Aging Level

The Grant pays for an Alzheimer's disease coordinator at each of the area agencies on Aging to provide dementia expertise and respite service administration. The responsibilities of the coordinators include conducting assessments and intake of new clients, providing information and assistance, on-going care management, and monitoring of clients receiving state respite services.

State Government

During the early and mid 1990s, the Grant focused on improving the capacity to respond to the immediate needs of persons with Alzheimer's disease and their families and to promote system development. Because the Project Director's office was located within the offices of the policy makers in Bureau of Elder and Adult Services, her presence provided an accessible and ready Alzheimer's expertise to state government. As the Grant initiatives were implemented, the state incorporated many of these initiatives into its ongoing programs of home- and community-based services. However, some of the Grant initiatives proved unsuccessful, and the staff time and resources were redistributed to other efforts. The availability of the funding, the consistency of Grant activities with state policy initiatives, and the availability of Alzheimer's disease/dementia expertise increased the impact of the Grant.

Maine Alzheimer's Association

One of the early objectives of the first Grant (1992–2000) was to enhance the capabilities of the then-Southern Maine Alzheimer's Association. The goal was to have them serve as a statewide organization that would enhance consumer knowledge and service options on Alzheimer's disease. This initiative was successful, and the Association now provides services across the state. Using Grant funding, the Alzheimer's Association developed and conducted educational workshops for family caregivers, hospital staff, clergy, and police; created an information and referral service; implemented and maintained a consumer help line; developed a database of Alzheimer's disease resources in each community; wrote a manual describing how to serve memory-impaired residents in senior housing;[3] and participated in the original Best Friends training. One of the Alzheimer's Association staff is a master Best Friends trainer and offers training across the state. All of these initiatives were initially funded with seed money from the Grant but were subsequently absorbed into the general programming and budget of the Alzheimer's Association.

Identifying People in Need by Improving Diagnosis

Obtaining a diagnosis of Alzheimer's disease is an important first step in coping with the illness and its consequences. Similar to other rural areas throughout the country, Maine contends with difficulty in recruiting and retaining physicians, especially those with expertise in older people (Turyn, 2001). A key strategy of the Grant is to improve the ability of physicians to diagnose people with Alzheimer's disease.

Establishing Geriatric Diagnostic Centers

In the early 1990s, Maine had only one geriatric diagnostic center; waiting times for an appointment averaged 4 to 5 months and people were forced to travel long distances, which many families were unwilling or unable to do (Turyn, 2001). Additionally, a survey of physicians conducted by the University of Southern Maine found a need for additional capacity to diagnose dementia or Alzheimer's disease (Fortinsky and Wasson, 1997). To address this problem, the Grant developed three additional evaluation units in three separate parts of the state. One of the units was located in a medical school; the second was in a health center; and the third, and most innovative, operated out of a home health agency and traveled to the homes of individuals being evaluated. Today, only the university-based center remains operational. The in-home evaluation team model could not be sustained because Medicare cuts eliminated social work support. The fact that the geriatrician did not meet with the individual as part of the assessment prevented the billing of Medicare for these services. Reduced state funds, staff turnover, and changing priorities at the Bureau of Elder and Adult Services further stymied the sustainability of the other diagnostic centers.

The mobile evaluation team model comprised a nurse, a social worker, and a geriatrician (Turyn, 2001). Using standardized tools, the nurse and social worker traveled to the home and assessed the mental status, level of functioning, stress, anxiety and depressive symptoms, physical and health status, dementia history, medications, and behavioral symptoms of the individual. The team also ascertained the level of caregiver stress, depressive symptoms, and health and emotional problems. The findings of the assessment and interviews and any information provided by the primary care physician were reviewed with the off-site geriatrician. The team then developed recommendations, and one member of the team returned to the home to explain the findings and assist in implementing the care plan with the family. The recommendations were also shared with the family's primary care physician. While the mobile team met the needs of rural residents who are unable or unwilling to travel, for the reasons stated previously, this program was not financially sustainable.

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[3] The manual is available on the Administration on Aging Web site: http://www.aoa.gov/alz/media/memory_impaired.asp.

Physician Education Project

To improve primary care physicians' skills in diagnosing Alzheimer's disease and related dementias, the Grant funded the Rural Alzheimer's Education Project from a one-time U.S. Health Resources and Services Administration allocation in 1999. Funding for this project was continued with the 2000–2004 ADDGS Grant. Physicians at rural health centers were taught differential diagnoses of Alzheimer's disease and dementias, behavior management techniques that would be effective for family members to use at home, and the types of community resources available to caregivers (Turyn, 2001). The training team traveled to the health center to conduct the training and tailored the trainings to meet the needs of each center.

Changing the Assessment Form

As part of the compromise reached by the stakeholders in 1996, the state agreed to create and implement an expanded screening tool to assess the level of cognitive and behavioral impairment of persons thought to have Alzheimer's disease or dementia. The Project Director participated in this process as a member of the stakeholders group. The new tool captured the level of functioning and need for assistance that was not a component of the earlier assessment.

Better Linking People to Services

Persons with Alzheimer's disease and their family caregivers often are not aware of their options and the services available to them. As a result, many persons with Alzheimer's disease do not get the services they need. To address this problem, the Grant invested in a variety of projects to better link people to services.

Assessment Counseling

Initiated during the 2000–2004 Grant period and continuing today, the Grant supports a portion of the salary of a staff person at Goold Health Services who works with individuals with Alzheimer's disease or their family members (if more appropriate) who are determined eligible but have not yet initiated publicly supported care or are denied home- and community-based services because they do not meet financial or functional eligibility criteria. Goold Health Services does the functional assessment for all persons who seek publicly supported long-term care in Maine. For individuals or families determined to be eligible for assistance, the staff will review the process, outcomes, and range of options available with them. A follow-up call is made approximately 1 month later to inquire about the status of obtaining services. If an individual is determined ineligible for services, the staff member contacts the individual to review his/her right to appeal the assessment and answer any questions. The staff member also reviews the referrals made to other services during the assessment.

Increase Use of Hospice Services

Many individuals are not aware that Alzheimer's disease is a terminal illness. Often, family members of persons with the disease would prefer their relative to die with the palliative care offered by hospices, but they do not use the service because of ignorance about it, resistance by physicians, or unwillingness to recognize that the individual is dying.

To increase the number of referrals for persons with dementia, the Grant contracted with a geriatrician specializing in end-of-life care and Alzheimer's disease and with the Maine Hospice Council to facilitate a series of focus groups. The purpose of the focus groups was to identify the barriers to using hospice services and to conduct three statewide trainings on end-of-life care and Alzheimer's disease and dementia. The trainings included basic information on the progression and effects of Alzheimer's disease, when hospice is an appropriate referral, what the goals of care should be (e.g., comfort versus longevity), education on the language to use with medical providers, and the differences between Medicare and Medicaid hospice benefits.

Starting in May 2005, these statewide trainings were available to staff at adult protective services, the nurse assessors at Goold Health Services, certified nurse assistants, nurses, social workers, care coordinators at Elder Independence of Maine, staff at the Area Agencies on Aging, and respite program administrators. The expectation was that training a wide range and number of staff would increase the visibility of hospice as an option. In addition, both Elder Independence of Maine and Goold Health Services have changed their intake forms to include hospice as a service option. To assess the impact of the trainings, the Grant will track the number of people referred to hospice from the various agencies. Between May 1, 2005 and August 1, 2005, 11 referrals to hospice had been made. The Grant also provides funding for the geriatrician to consult with families, home care staff, and physicians when barriers to entering hospice arise in individual cases. The purpose of working with physicians and other staff individually is to improve knowledge and change behaviors regarding end-of-life care.

Alzheimer's Coordinators

Area Agencies on Aging arrange for many services directly and refer clients to others. The services available to seniors through the agencies include adult day care, care management, caregiver assistance, congregate housing services, senior companion, health insurance counseling, home repair and maintenance, money management assistance, nutritional services, resource information and referral, respite services, senior advocacy, and assistance and volunteer opportunities. To improve coordination of services for persons with Alzheimer's disease and for their families, the Bureau of Elder and Adult Services contracts with each of the Area Agencies on Aging to include an Alzheimer's coordinator who administers the state-funded respite care program for caregivers of persons with Alzheimer's disease. The coordinator's salary is paid by the Grant. These coordinators are usually colocated with the National Family Caregiver Support Program staff at the Area Agency on Aging. Both programs work collaboratively together to ensure caregivers receive the appropriate services.

Mental Health Screening

To determine if family caregivers receiving services are depressed or have other mental health problems, Grant funds are used to implement an intake form that is included on a statewide mental health screening tool used, primarily by the Alzheimer's coordinators in conjunction with the caregiver program.[4] Based on the scoring of questions about stress, burden,

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[4] This tool was developed with funding by a U.S. Administration on Aging's National Family Caregiver Support Program Grant awarded to the Eastern Agency Area on Aging and the University of Maine, Center on Aging as part of the Maine Primary Partners in Caregiving Project. As part of the project, patients going to their primary care physician are screened using this tool. If the responses indicate potential depression and the patient agrees,

and depression, the screening tool identifies caregivers in need of additional mental health services. These caregivers are then referred to the newly developed mental health service programs. Additionally, this intake form is also used by the staff at Elder Independence of Maine to assess whether caregivers would benefit from short-term mental health counseling. The intake form is a modification of the form developed by Montgomery (2002) as part of her earlier study of the ADDGS program.

Expanding Availability of Services

One of the principal goals of the ADDGS Grants is to expand access to home- and community-based services for people with Alzheimer's disease and their families. In Maine, grant funds were invested in several new services. Concurrently, strategies were pursued to ensure that these services would continue after the Grant ended. These services generally sought to strengthen the informal support provided by family rather than providing services directly to the person with Alzheimer's disease.

Respite Care

An early objective of the first Maine ADDGS Grant was to establish three volunteer in-home respite programs to serve the central, northern, and eastern parts of the state. These programs were patterned after the existing Alzheimer's Association program in Southern Maine. However, partly because of the rural nature of the rest of the state and the large distances necessary to travel, the volunteer aspect of the program was not successful. In some areas, no volunteers were available to provide services, in part because travel distances were so great. In other areas, volunteers were available but no families were identified as needing services. The Grant changed focus to develop a paid respite program instead.

As part of the shift in state policy towards home- and community-based services, the state incorporated the ADDGS-funded model of respite care into the state's home- and community-based services system. Effective November 1, 1997, the state covered respite care services under the home- and community-based services waiver. In addition, the state created its own state-funded respite care program with financial eligibility higher than Medicaid. Individuals are allowed up to $3,800 to obtain respite services in the individual's home, in a licensed adult day care program, or in an institutional setting. Responsibility for administering the state respite service was given to Area Agencies on Aging. Implementation went smoothly, in part because the Area Agencies on Aging were already involved in respite care through the ADDGS Grant. Between July 1, 2000 and December 31, 2004, 2,573 families received respite services through the state-funded program. The state uses respite services to meet the federal requirements that 50 percent of the Grant be used for direct services and to provide the state match for federal funds.

Caregiver Companion Program

Beginning in April 2002, Elder Independence of Maine used Grant funds to hire three part-time unlicensed staff to serve as caregiver companions in designated rural counties. The

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the physician will refer the patient for mental health services. The intention is to make connections as soon as possible to support caregivers in their role.

program provides services to any caregiver whose family member has Alzheimer's disease and is receiving home- and community-based services through MaineCare (Maine's Medicaid program) or through state-funded programs. The program objectives are to reduce caregiver stress, burden, and depression using individualized support and education to the caregiver through a combination of in-home visits, telephone calls, and other activities based on the needs and preferences of the caregiver. The types of activities the caregiver companion provides include:

- Providing information (e.g., books and informational brochures) about the disease.
- Taking the caregiver out for a meal.
- Planting flowers.
- Cooking with the caregiver.
- Accompanying the caregiver to support group meetings.
- Assisting the caregiver to re-engage in meaningful activities.
- Taking care of him- or herself mentally, physically, and spiritually.

According to the Project Director, the program's goal is to support the caregiver because "they're really the backbone of the home care system. If something happens to them, the whole care plan for the person could be in jeopardy" (The Rural Monitor, 2004). The maximum number of caregivers being served at one time is between 75 and 80 people. The program began during the 2000–2004 Grant and continues with an expanded area of service for this current Grant period (2004–2007). During the 2000–2004 Grant, 135 caregivers received services, and 65 caregivers participated in the program between July1, 2004 and December 31, 2004. This program was based on research conducted by Mittelman and colleagues (1996), who found that counseling and social support can increase the time caregivers are able to care for persons with Alzheimer's disease at home, especially during the early to middle stages of dementia.

In an effort to assess the effectiveness of the Caregiver Companion Program and to build support for its continuation after the Grant ends, the Grant provided funding for research staff at the University of Southern Maine to conduct a formal evaluation of the program in 2005. The evaluation included measures developed by Montgomery (2002) to assess objective and subjective stress and level of burden. Preliminary analyses of the pilot program evaluation are mixed. While the measure for objective burden showed that the caregivers' burden declined on average over the course of the study, the other measures showed no statistically significant improvement in the caregiver's subjective burden or level of depression. At this time, the state does not intend to allocate additional funds to conduct further evaluation.

Mental Health Counseling

As part of the current Grant, funding is provided to each of the five Area Agencies on Aging to develop short-term mental health counseling to depressed caregivers. Research suggests that caregivers have significantly fewer symptoms of depression after receiving counseling and support and were less likely to place the family member in a nursing facility in the early to middle stages of Alzheimer's disease or dementia (Mittelman et al., 1996). Each Area Agency on Aging developed a program to provide up to three sessions to caregivers.

Improving Quality of Care through Training

The quality of long-term care services is likely compromised by the vacancies, high turnover, and the low levels of training of long-term care workers. Many long-term care workers lack training specifically in Alzheimer's disease even though persons with the disease account for a substantial portion of their caseload. The vacancies mean that long-term care providers are short staffed and even at full staffing may have inadequate numbers of personnel. High turnover also means that continuity of care is reduced, with staff not having time to get to know the needs and preferences of individual consumers. Workers who are providing care in understaffed environments may experience high levels of stress and frustration, which may lead to high turnover and poor quality of care. To address this problem, the Grant supported initiatives that are now a regular part of the ongoing training system in Maine.

Best Friends Training

Initiated with funding from the 2000–2004 Grant and now primarily financed with state funds, training in the Best Friends Approach to Alzheimer's care is provided to staff from nursing and residential facilities, Area Agency on Aging, adult day care, and home care agencies. Alzheimer Association staff and other professionals were trained as master trainers and travel throughout the state conducting trainings. This approach, developed by Bell and Troxel (2003) in their book The Best Friends Approach to Alzheimer's Care for the Oregon ADDGS Grant, uses a person-centered model that emphasizes looking first at the person and then focusing on the behaviors that need changing. Caregivers or staff are taught to emphasize and accept the loved one's (or client's) situation and to develop different caregiving strategies by being a "best-friend" to the person with dementia (Coburn and Morris, 2003). The project uses a "train-the-trainer" format and consists of six modules conducted over 12 hours.

As a way of institutionalizing the training at the facilities and agencies and addressing the high turnover rate among direct-care workers, administrators, departmental managers, and direct-care supervisors are required to participate in the trainings. The goal is to change the organizational culture. In each of the facilities, different levels of staff are expected to partner with each other and spend a few minutes each day learning the partners' life story; according to the curriculum, this allows staff to gain a sense of being cared for and embodies the program philosophy. To support the ongoing use of the training, each facility identifies a liaison who maintains monthly contact with Grant staff and attends semiannual meetings. This training is also available in a modified format to family members.

From October 2000 to June 2005, 135 Best Friends trainings were conducted with 117 agencies/programs and approximately 2,500 staff (Maine Bureau of Elder and Adult Services, 2005) were trained. No quantitative evaluation of this training has occurred. The University of Southern Maine conducted a satisfaction survey of participants in 2002, which found that participants were very positive about the program. The university submitted an evaluation proposal to the Robert Wood Johnson-funded "Better Jobs Better Care" program in 2003, but it was not funded.

Training for Residential Facility Administrators

As part of the commitment to increase and improve nonnursing home options for people with Alzheimer's disease, the Grant collaborated with the Maine Alzheimer's Association to seek funding from the UNUM Foundation[5] to improve care for Alzheimer's patients at residential care facilities. This funding was awarded to the Maine Alzheimer's Association to develop the materials and the training. Training was provided to five facility administrators to create "centers of excellence" on serving people with Alzheimer's disease. The intention was to create a "train-the-trainer" model, with the administrators then training the direct-care staff. This effort was ultimately unsuccessful because the trained staff left the facilities and the training was not ongoing.

Integrating Acute and Long-Term Care Services

Individuals with disabilities typically are high users of both acute and long-term care services. These services, however, are typically fragmented, with Medicare and the federal government dominating acute care and Medicaid and the states dominating long-term care. A number of states, including Maine, have initiatives to improve services to persons with disabilities by integrating acute and long-term care services and financing. The Grant sought to bring an Alzheimer's disease and dementia care component to this state initiative.

Early in the 2000–2004 Grant period, the state initiated a program designed to combine acute and long-term care services for persons dually eligible for Medicare and Medicaid in a rural setting. MaineNET, a demonstration project funded by U.S. Health Care Financing Administration[6] and the Robert Wood Johnson Foundation, was originally implemented as a primary care case management program in three counties. The Grant sponsored special services for people with Alzheimer's disease or dementia, including increasing the coordination between the primary physician and the long-term care system, assisting physicians and insurers to adopt tools to better work with Alzheimer's families; improving accessibility to memory evaluation services; and providing earlier support and information to families and caregivers of Alzheimer's patients, including respite services.

The pilot project included a case manager located in the physician's office. Despite the goal of improving coordination, program enrollment was small because of the unwillingness of beneficiaries to voluntarily enroll. Although the coordination activities were considered helpful by the participating Medicaid beneficiaries and their physicians, the program was not financially sustainable because of small caseloads. As a result, the state decided not to continue the

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[5] UnumProvident Corporation is a publicly owned insurance holding company formed by the June 30, 1999, merger of UNUM Corporation of Portland, Maine, and Provident Companies, Inc. of Chattanooga, Tennessee. The Foundation is a charitable component within the Corporation.

[6] The U.S. Health Care Financing Administration is now the U.S. Centers for Medicare & Medicaid Services.

demonstration project because of the expense, difficulty with statewide implementation, and low likelihood of Medicaid paying the cost of care coordination and support.

The program was redesigned into a population-based chronic care disease management model designed to improve coordination of care for dually eligible beneficiaries by working directly with primary care physicians, particularly by using an aggressive medication management program. The revised program did not include a long-term care component, and the Grant shifted resources and staff time to other initiatives. Basing the Grant's activities on another demonstration was a risk, which in this case did not work out.

Leveraging ADDGS Funds/Sustainability

The ADDGS program is a demonstration program, which does not provide permanent funding for services. The Maine program is keenly aware of that fact and has sought to obtain permanent funding from the state and to obtain additional funds from other sources. The Grant has been highly successful in leveraging funding to supplement Grant dollars. Examples of successful leveraging include the following:

<u>State Government</u>

- Starting in 1996, the state provided supplemental funding for the respite program ($255,000) and provided funding directly to adult day care facilities for the care of individuals with Alzheimer's disease or dementia ($200,000).

- From 2000 to date, the Best Friends training obtained funding from several state agencies, including the Department of Human Services, the Division of Licensing and Certification, the Division of Residential Services, and the Department of Behavioral and Developmental Services in addition to $20,000 per year from the Bureau of Elder and Adult Services. These funds are used to supplement Grant training efforts.

- Grant funds are used at Goold Health Services, Elder Independence of Maine, and each of the Area Agencies on Aging to supplement salaries of staff who focus on Alzheimer's disease or dementia. In each instance, the Grant agreed to fund a portion of a staff position for a specific amount of time to conduct particular tasks. This funding was contingent on the partnering agency providing the remaining portion of the salary.

<u>Federal Government</u>

- In 1999, an additional $30,000 was received from the U.S. Health Resources and Services Administration to create additional training opportunities for primary care physicians located in rural health centers. Under the Grant, a physician was hired to conduct trainings in the proper diagnosis of Alzheimer's disease at 14 sites across the state. As part of these trainings, a physician evaluated and diagnosed a person with Alzheimer's disease while other physicians watched.

- In 1999, additional U.S. Health Resources and Services Administration funds were obtained to create a part-time help line position at the Alzheimer's Association, to hire an Alzheimer specialist staff person at Elder Independence of Maine to provide in-home education and support to individuals or families diagnosed with Alzheimer's disease, and to continue the training for physicians.

Foundations

- From 1996 to 2000, the Brookdale Foundation approached the Grant and agencies offering respite services and offered funding to develop group respite programs that provided social and recreational activities for persons with Alzheimer's disease and supply individual respite care to family members and other primary caregivers. Additionally, the foundation offered funding for programs in which family caregivers could access supportive services such as counseling, support groups, information and referral, and training and education. A total of five sites received Foundation funds. Grant funds supplemented Brookdale funds with in-kind support. As of August 2005, three of the sites continue to operate.

- In 1998, the state collaborated with the Maine Alzheimer's Association to obtain a Grant from the UNUM Foundation for funding to develop a "train-the-trainer" model for administrative staff at residential care facilities to better meet the needs of Alzheimer's patients. The state subcontracted the task to the Alzheimer's Association to develop the materials and conduct the training sessions.

CONCLUSION

In its 13 years of operation, the Maine ADDGS program succeeded in changing the long-term care system of Maine in many ways, including establishing a state-funded respite program, helping to reform the eligibility standards for nursing home care, creating a widely used training program, and improving the availability of diagnostic services. As befits a demonstration program, however, not all of its initiatives were successful. For example, its efforts to establish "centers of excellence" for residential care facilities and the MaineNET initiatives did not work out. In addition, the program faced numerous barriers ranging from the general problems of providing services in a rural environment to the resistance of some state policy makers to tailoring policies to persons with Alzheimer's disease. To achieve systems change, the Maine ADDGS program used a number of strategies, including:

- Operating demonstration projects that could be implemented statewide. From the beginning, expanding respite services was a major focus of the Grant. As a result, starting in 1996 when state long-term care policy shifted to expanding home- and community-based services, the ADDGS respite care program was an ongoing model that the state could adopt and build on. The development of home- and community-based services for people with Alzheimer's disease was particularly needed because of changes in nursing home eligibility criteria. The state now operates its own state-funded respite program for those not eligible for the home care 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 implemented 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 the Grant is on linking people with the larger care system. Thus, for example, the goal of the Alzheimer's disease specialist at Goold Health Services is to help individuals and their families navigate the existing service delivery system, and the goal of the hospice initiative is to increase use of the already established Medicare- and Medicaid-funded hospice benefit.

- Building Alzheimer's disease technical expertise at the state, Area Agencies on Aging, consumer, and provider levels. The Grant consistently sought ways to increase knowledge of Alzheimer's disease and to apply it to financing and services for people with Alzheimer's disease and their families. Thus, at the state level, the Project Director was consulted on state policies, such as revising the assessment form for publicly funded services, that had a major impact on persons with Alzheimer's disease and their families. The funding of the Alzheimer's disease coordinators at the Area Agencies on Aging was designed to provide a similar level of expertise at the local level. In addition, other initiatives sought to educate doctors on Alzheimer's disease. While changing the behavior of physicians is not easy, once established in a community, they are relatively likely to stay and practice for long periods of time.

Finally, the projects with the Alzheimer’s Association were designed to build consumer capacity and expertise.

- Establishing ongoing training programs using already established curriculum. The Grant incorporated the already established and tested Best Friends training for Alzheimer’s disease services and institutionalized it as a regular training program. The strong positive response of providers to the training means that large numbers of staff, at all levels, were taught the tools to better provide services to persons with Alzheimer’s disease. The state invested some of its own resources into the training, and the Grant has tried, with modest success, to include state inspection staff in the training as well as providers. As with all training in long-term care, high turnover rates mean that persons receiving the training do not necessarily stay within the field. The program addressed the problem by giving the training to higher level administrators and by establishing an ongoing relationship with facilities and agencies receiving the training.

- Embedding the initiative in larger organizations and ongoing activities. In several instances, such as the assessment worker at Goold Health Services and the Alzheimer’s coordinators at the Area Agencies on aging, 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.

- Funding research to demonstrate the value of Grant-funded activities. To systematically show the benefits of some of its initiatives, such as the Caregiver Companion Program, the Grant funded research to evaluate the effectiveness of its services and initiatives. The hope is that programs that produce quantifiable benefits will generate more support for government funding.

- Leveraging ADDGS program funds. The Grant worked hard to raise funds from other funding sources, including foundations and state government. For example, the Grant obtained funds to expand respite care programs from the Brookdale Foundation and funds from the state for the Best Friends staff training.

In sum, over its 13 years of operation, the Maine ADDGS program was involved in a large number of initiatives that ranged from early diagnosis to end-of-life care. Through a variety of strategies, the Grant has changed the financing and delivery system for people with Alzheimer’s disease and their families in the state of Maine.

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