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# Alzheimer's Disease Demonstration Grants to States Program: New York

## Final Report

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NEW YORK**

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## EXECUTIVE SUMMARY

In July 2002, the New York State Office on Aging (NYSOFA) implemented its first 3-year Alzheimer's Disease Demonstration Grants to States (ADDGS) grant designed to increase the ability of persons with developmental disabilities and symptoms of Alzheimer's disease to age in place in spite of their disease progression. NYSOFA selected this dual-diagnosis population because of the growing body of research indicating that individuals with developmental disabilities, particularly those with Down Syndrome, have a much larger risk of suffering from Alzheimer's disease (Janicki and Dalton, 1999). Furthermore, because of advances in medical care, the longevity of this population has increased and a growing number of New York State residents will require services from both the aging and developmental disabilities networks.

The two primary goals of this grant included: (1) creating a model for providing home and community-based services to persons with both developmental disabilities and symptoms of Alzheimer's disease and their caregivers; and (2) demonstrating the effectiveness of an approach that blended Alzheimer's disease, aging, and developmental disabilities support and management strategies, and increased collaboration and cross-agency responses to the home and community-based service needs of this population (McCallion and McCarron, 2002).

In July 2005, NYSOFA began implementing the second ADDGS grant, which is designed to create a dementia-capable single point of entry (POE) that utilizes a county-based long-term care central assessment system and works with existing state-funded Alzheimer's disease screening and service delivery system in rural areas and ethnically diverse small cities (McCallion and Harazin, 2005; New York State Office for the Aging, 2006). Through the grant, two counties integrated dementia services, education, and training with the existing county-based long-term care POE system. Previously, an individual with Alzheimer's disease or family member requesting supports or services would have received fragmented care or been referred to the Alzheimer's Association for Alzheimer's disease-related assistance. Within the newly integrated system, the Alzheimer's Association staff and Area Agency on Aging case manager provide information and access to a full range of services related to long-term care.

Individuals living in rural areas and persons who are ethnically diverse and living in small cities are of particular concern to NYSOFA officials because few services and supports are currently available to them. Additionally, some services available to individuals in large urban areas are not necessarily available to those individuals residing in small cities or rural areas (McCallion and Harazin, 2005).

**Exhibit ES-1** summarizes findings for the Coordinated Care grant and intended outcomes for the Point-of-Entry grant with respect to the four key study questions for each grant.

## Exhibit ES-1. Coordinated Care Grant Key Findings and Point-of-Entry Grant Intended Outcomes

### Coordinated Care Grant—Key Findings

How has the grant enhanced access to services for individuals with developmental disabilities and Alzheimer’s disease?

The grant:

- Trained developmental disabilities providers and family members to recognize the symptoms of dementia, secure a diagnosis of dementia, identify levels of need for dementia-appropriate services and supports and environmental modifications, and create dementia-specific care plans.
- Surpassed the stated goal of allowing 150 individuals with developmental disabilities and Alzheimer’s disease to age in place in community residences with direct services, supports, and environmental modifications.

How has the grant enhanced the availability and quality of services for individuals with developmental disabilities and Alzheimer’s disease?

The grant:

- Created a network of providers offering dementia-appropriate direct services (e.g., staff time to help get ready for attending a day program) and supports (e.g., support groups).
- Changed physical surroundings at day programs and community residences that provided a more appropriate space (e.g., simpler environment) and augmented the value of the more traditional direct services administered through the grant.

How has the grant enhanced the quality and availability of a competent workforce for those with developmental disabilities and Alzheimer’s disease?

The grant:

- Provided dementia-specific training and education to more than 1,000 individuals, including direct care workers, family members, and social workers.
- Enhanced capacity of staff to identify early signs of Alzheimer’s disease in the developmental disabilities population and become more skilled at working with this population, increasing referrals by developmental disabilities providers for dementia-appropriate long-term care services.

(continued)

**Exhibit ES-1. Coordinated Care Grant Key Findings and Point-of-Entry Grant Intended Outcomes (continued)**

**Coordinated Care Grant—Key Findings (continued)**

What impacts has the grant had on state and local policies, procedures, and funding for services for individuals with developmental disabilities and Alzheimer’s disease?

The grant:

- Leveraged additional funding for grant partners from other state agencies and foundations to continue dementia services to the aging developmental disabilities population.
- Led to a care planning process for Medicaid day program services for people with developmental disabilities and Alzheimer’s disease that maintain skills and ensure quality of life, rather than aim to increase skills.

**Point of Entry Grant—Intended Outcomes**

How will the grant enhance access to services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Provide Alzheimer’s disease services through the single-point-of-entry system creating an environment where individuals no longer have to seek services from multiple locations or providers.
- Enable individuals with Alzheimer’s disease to remain in the community longer because of comprehensive needs assessments, the development of dementia-specific service plans, and provision of caregiver supports.

How will the grant enhance the availability and quality of services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Provide dementia-appropriate services and coordinate services between providers and clients.
- Meet the needs of persons with Alzheimer’s disease and their family caregivers in rural and small ethnically diverse cities by hiring a dementia-specific case manager to manage and deliver all diagnostic and direct care services.
- Develop a directory for targeted geographic areas listing available support resources.

(continued)

**Exhibit ES-1. Coordinated Care Grant Key Findings and Point-of-Entry Grant Intended Outcomes (continued)**

**Point of Entry Grant—Intended Outcomes (continued)**

How will the grant enhance the quality and availability of a competent workforce for those with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Establish a competent workforce for people caring for persons with Alzheimer’s disease and other dementias by connecting families, long-term care service providers, case managers, clergy, and medical providers with dementia-specific training; providing informational and educational materials, and serve as a portal to access community resources, information, and other long-term care service options.
- Support the ongoing education of a dementia-capable workforce by producing train-the-trainer modules.

What impacts will the grant have on state and local policies, procedures, and funding for services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Create a dementia services network within the long-term care system and a replicable program model based on the collaboration among grant partners, specifically between dementia-appropriate service providers and POE staff.
- Move intensive dementia case management facilitated by the integration of point-of-entry staff with Alzheimer’s disease expertise and knowledge of related services into the long-term care point-of-entry case management team, resulting in a more comprehensive care plan.
- Install a formal mechanism for addressing dementia needs in long-term care planning through commitments by POE system leaders to sustain the position of dementia specialists on case management teams.

## SECTION 1 INTRODUCTION

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 focuses on serving hard-to-reach and underserved people with Alzheimer's disease or related disorders (U.S. Administration on Aging, no date).

This report describes one of four case studies conducted by the ADDGS National Resource Center in 2006 on the activities of selected State programs.<sup>1</sup> The New York State Office on Aging was selected because of the State's concerted efforts to: (1) develop an innovative approach to provide services to persons with developmental disabilities and Alzheimer's disease and their caregivers; and (2) incorporate persons with Alzheimer's disease into the population being served by county long-term care point-of-entry (POE) systems, especially people in rural and ethnically diverse communities.

The U.S. Administration on Aging has awarded New York two ADDGS grants. The State's first grant (2002-2005), the Coordinated Care grant, resulted in a better understanding by developmental disabilities providers and caregivers of the impact of dementias on the developmental disabilities population; an increase in the number of referrals to long-term care providers; and the provision of dementia-appropriate long-term care services to persons with developmental disabilities and Alzheimer's disease in the Rochester and Albany (Capital Region) areas. The second ADDGS grant (2005-2008), the Point-of-Entry grant, is including persons with Alzheimer's disease in Fulton and Oneida Counties' long-term care single point-of-entry systems.

The report addresses the following four research questions for each grant:

### *Coordinated Care Grant*

- How has the grant enhanced access to services for individuals with developmental disabilities and Alzheimer's disease?
- How has the grant enhanced the availability and quality of services for individuals with developmental disabilities and Alzheimer's disease?
- How has the grant enhanced the quality and availability of a competent workforce for individuals with developmental disabilities and Alzheimer's disease?

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<sup>1</sup> Two case studies are of the Michigan and Minnesota ADDGS grants, and a fourth report is focusing on minority populations across a number of states.

- What impacts has the grant had on state and local policies, procedures, and funding for services for individuals with developmental disabilities and Alzheimer’s disease?

*Point-of-Entry Grant*

- How has the grant enhanced access to services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?
- How has the grant enhanced the availability and quality of services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?
- How has the grant enhanced the quality and availability of a competent workforce for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?
- What impacts has the grant had on state and local policies, procedures, and funding for services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

**Exhibit 1** summarizes findings for the Coordinated Care grant and intended outcomes for the Point-of-Entry grant with respect to the four key study questions for each grant.

Information for this case study came from reviews of administrative files at the U.S. Administration on Aging and various Web sites, an in-person site visit in Utica and Rochester, New York, from July 25–26, 2006, and several telephone interviews with grant partners. An RTI International staff member and a consultant met in person with or spoke by telephone to staff representing the following entities:

- New York State Office on Aging (State Unit on Aging),
- Bureau of Chronic Disease Services within the New York Department of Health,
- Finger Lakes Developmental Disability Service Office (DDSO) (a regional office of the State Office for Mental Retardation and Developmental Disability (OMRDD),
- Four Area Agencies on Aging,
- Three New York State chapters of the Alzheimer’s Association,
- State University at Albany’s Center for Excellence in Aging Services,
- University of Rochester’s Program in Aging & Developmental Disability within the Strong Center for Developmental Disabilities, and
- Monroe and Wayne County ARCs.

They also attended an advisory board meeting for the Oneida County Point-of-Entry grant.

## **Exhibit 1. Coordinated Care Grant Key Findings and Point-of-Entry Grant Intended Outcomes**

### **Coordinated Care Grant—Key Findings**

How has the grant enhanced access to services for individuals with developmental disabilities and Alzheimer’s disease?

The grant:

- Trained developmental disabilities providers and family members to recognize the symptoms of dementia, secure a diagnosis of dementia, identify levels of need for dementia-appropriate services and supports and environmental modifications, and create dementia-specific care plans.
- Surpassed the stated goal of allowing 150 individuals with developmental disabilities and Alzheimer’s disease to age in place in community residences with direct services, supports, and environmental modifications.

How has the grant enhanced the availability and quality of services for individuals with developmental disabilities and Alzheimer’s disease?

The grant:

- Created a network of providers offering dementia-appropriate direct services (e.g., staff time to help get ready for attending a day program) and supports (e.g., support groups).
- Changed physical surroundings at day programs and community residences that provided a more appropriate space (e.g., simpler environment) and augmented the value of the more traditional direct services administered through the grant.

How has the grant enhanced the quality and availability of a competent workforce for those with developmental disabilities and Alzheimer’s disease?

The grant:

- Provided dementia-specific training and education to more than 1,000 individuals, including direct care workers, family members, and social workers.
- Enhanced capacity of staff to identify early signs of Alzheimer’s disease in the developmental disabilities population and become more skilled at working with this population, increasing referrals by developmental disabilities providers for dementia-appropriate long-term care services.

(continued)

**Exhibit 1. Coordinated Care Grant Key Findings and Point-of-Entry Grant Intended Outcomes (continued)**

**Coordinated Care Grant—Key Findings (continued)**

What impacts has the grant had on state and local policies, procedures, and funding for services for individuals with developmental disabilities and Alzheimer’s disease?

The grant:

- Leveraged additional funding for grant partners from other state agencies and foundations to continue dementia services to the aging developmental disabilities population.
- Led to a care planning process for Medicaid day program services for people with developmental disabilities and Alzheimer’s disease that maintain skills and ensure quality of life, rather than aim to increase skills.

**Point of Entry Grant—Intended Outcomes**

How will the grant enhance access to services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Provide Alzheimer’s disease services through the single-point-of-entry system creating an environment where individuals no longer have to seek services from multiple locations or providers.
- Enable individuals with Alzheimer’s disease to remain in the community longer because of comprehensive needs assessments, the development of dementia-specific service plans, and provision of caregiver supports.

How will the grant enhance the availability and quality of services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Provide dementia-appropriate services and coordinate services between providers and clients.
- Meet the needs of persons with Alzheimer’s disease and their family caregivers in rural and small ethnically diverse cities by hiring a dementia-specific case manager to manage and deliver all diagnostic and direct care services.
- Develop a directory for targeted geographic areas listing available support resources.

(continued)

**Exhibit 1. Coordinated Care Grant Key Findings and Point-of-Entry Grant Intended Outcomes (continued)**

**Point of Entry Grant—Intended Outcomes (continued)**

How will the grant enhance the quality and availability of a competent workforce for those with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Establish a competent workforce for people caring for persons with Alzheimer’s disease and other dementias by connecting families, long-term care service providers, case managers, clergy, and medical providers with dementia-specific training; providing informational and educational materials, and serve as a portal to access community resources, information, and other long-term care service options.
- Support the ongoing education of a dementia-capable workforce by producing train-the-trainer modules.

What impacts will the grant have on state and local policies, procedures, and funding for services for individuals with Alzheimer’s disease, particularly among rural and ethnically diverse populations?

The grant will:

- Create a dementia services network within the long-term care system and a replicable program model based on the collaboration among grant partners, specifically between dementia-appropriate service providers and POE staff.
- Move intensive dementia case management facilitated by the integration of point-of-entry staff with Alzheimer’s disease expertise and knowledge of related services into the long-term care point-of-entry case management team, resulting in a more comprehensive care plan.
- Install a formal mechanism for addressing dementia needs in long-term care planning through commitments by POE system leaders to sustain the position of dementia specialists on case management teams.

The remaining sections of the report highlight the main features of the two New York ADDGS projects. Section 2 describes the Coordinated Care grant which began in July 2002 and ended in June 2005; section 3 describes the Point-of-Entry grant which started in July 2005 and will end in June 2008. The fourth section includes the conclusion.

## SECTION 2 COORDINATED CARE GRANT (JULY 1, 2002–JUNE 30, 2005)

In July 2002, the New York State Office on Aging (NYSOFA) implemented its first 3-year Alzheimer's Disease Demonstration Grants to States (ADDGS) grant, which was designed to increase the ability of persons with developmental disabilities and symptoms of Alzheimer's disease to age in place. NYSOFA selected this dually diagnosed population because of the growing body of research indicating that individuals with developmental disabilities, particularly those with Down Syndrome, have a much larger risk of suffering from Alzheimer's disease (Janicki and Dalton, 1999). Furthermore, because of advances in medical care, the longevity of this population has increased and a growing number of New York State residents will require services from both the aging and developmental disabilities service networks. NYSOFA responded to this need by creating a consortium of providers in two counties to implement the grant. Both counties had a large number of providers and a readiness to collaborate to provide services (McCallion and McCarron, 2002).

The two primary goals of this grant included: (1) creating a model for providing home and community-based services to persons with both developmental disabilities and symptoms of Alzheimer's disease and their caregivers; and (2) demonstrating the effectiveness of an approach that blended Alzheimer's disease, aging, and developmental disabilities support and management strategies, and increased collaboration and cross-agency responses to the home and community-based service needs of this population (McCallion and McCarron, 2002).

The target population for the grant comprised individuals with development disabilities who attended social and medical adult day care facilities and day programs and who resided in community settings (e.g., group homes and family-based care [foster family care]).<sup>2</sup> These individuals constituted a diverse group of persons aging with a range of developmental disabilities who experienced symptoms of Alzheimer's disease. Many clients had not been formally diagnosed with Alzheimer's disease and the majority of people were considered at risk for placement in more restrictive settings (Harazin and McCallion, 2005).

**Exhibit 2** lists the key objectives of the Coordinated Care grant.

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<sup>2</sup> Within the Office of Mental Retardation and Developmental Disabilities (OMRDD) system, three models of care provision are funded for persons with developmental disabilities: individualized residential alternatives (e.g., group home), community residences, and intermediate care facilities. Additionally, adult foster care is funded as a family-based care model.

## **Exhibit 2. Key Objectives of New York’s ADDGS Coordinated Care Grant**

- Increase access to dementia-appropriate long-term care services for persons with developmental disabilities and symptoms of Alzheimer’s disease by creating the capacity of developmental disabilities providers and family members to: recognize the symptoms of dementia, secure a diagnosis of dementia, and assess the need for dementia-appropriate services and environmental modifications, and create plans of care.
- Enhance the availability and quality of direct services for persons with developmental disabilities and Alzheimer’s disease by creating a network of providers offering dementia-appropriate direct services (e.g., staff time to help get ready for attending a day program) and supports (e.g., support groups) and implementing environmental modifications at day programs and community residences.
- Establish a competent workforce and educated caregiver community for persons caring for persons with developmental disabilities and Alzheimer’s disease.
- Increase referrals by developmental disability providers for dementia-appropriate long-term care services because staff are better able to identify early signs of Alzheimer’s disease in the developmental disabilities population and become more skilled at working with this population.
- Disseminate the model of services and training, the results of the evaluation, and the lessons learned to other regions of the state.
- Leverage ADDGS funds to sustain the program after grant funding ends.

### **Background**

Nationally, an estimated 140,000 adults have a diagnosis of developmental disability (including Down syndrome) and are potentially affected by Alzheimer’s disease (Janicki and Dalton, 1999). In 1999, the prevalence of Alzheimer’s disease in adults with developmental disabilities was 3 percent of adults age 40 and older and 6 percent of adults age 60 and older; for adults with Down syndrome, the rates were 22 percent and 56 percent, respectively (Janicki and Dalton, 1999). Because the number of people with Alzheimer’s disease is expected to increase in coming years as this population’s longevity increases, the growing concern among developmental disabilities and aging stakeholders prompted the examination of the availability of services for the aging developmental disabilities population by New York State officials. To address the aging population, the Governor implemented Project 2015, which involves planning, engagement, and action by 36 New York State government agencies to prepare for the impact of the aging population and the increasing diversity of the state’s population. NYSOFA is one of the agencies participating in this project.

In 2001, NYSOFA became aware that developmental disabilities and aging stakeholders<sup>3</sup> had formed a consortium to examine the needs of the aging developmental disabilities population. The consortium produced a white paper describing this special population's needs and possible solutions to meet those needs. The following is a selected list of issues identified in the report:

- access to specialized medical assessment/treatment;
- appropriate housing, including environmental assessments/modifications;
- caregiver supports;
- quality of life gaps;
- end of life issues; and
- advocacy and influence in the development of public policy (Community Partnership in Aging and Developmental Disabilities Services, 2000).

Based on the work of the consortium and at the direction of the Governor, NYSOFA and the State University at Albany's Center for Excellence in Aging Services developed a model to provide home and community-based services for individuals with both developmental disabilities and Alzheimer's disease, including low-income areas. The model presented in the grant application included two primary strategies to enable persons with developmental disabilities and Alzheimer's disease to age in place:

- Train a range of staff including administrators, supervisors, direct care staff, and family members on Alzheimer's disease and developmental disabilities-related topics. The intent was to give staff a better understanding of the impact of Alzheimer's disease on the developmental disabilities population and to make appropriate referrals for services.
- Create a provider network of professionals skilled at working with this population. The Alzheimer's Association created this network by subcontracting with providers known to the Area Agency on Aging and offering training to staff.

After the grant began, the grant stakeholders including NYSOFA, realized that providing funding for environmental assessments and modifications in community residences and day programs to ensure a safe physical environment was critical to maintaining the grant participant in the community. The U.S. Administration on Aging agreed to this strategy during the course of the grant.

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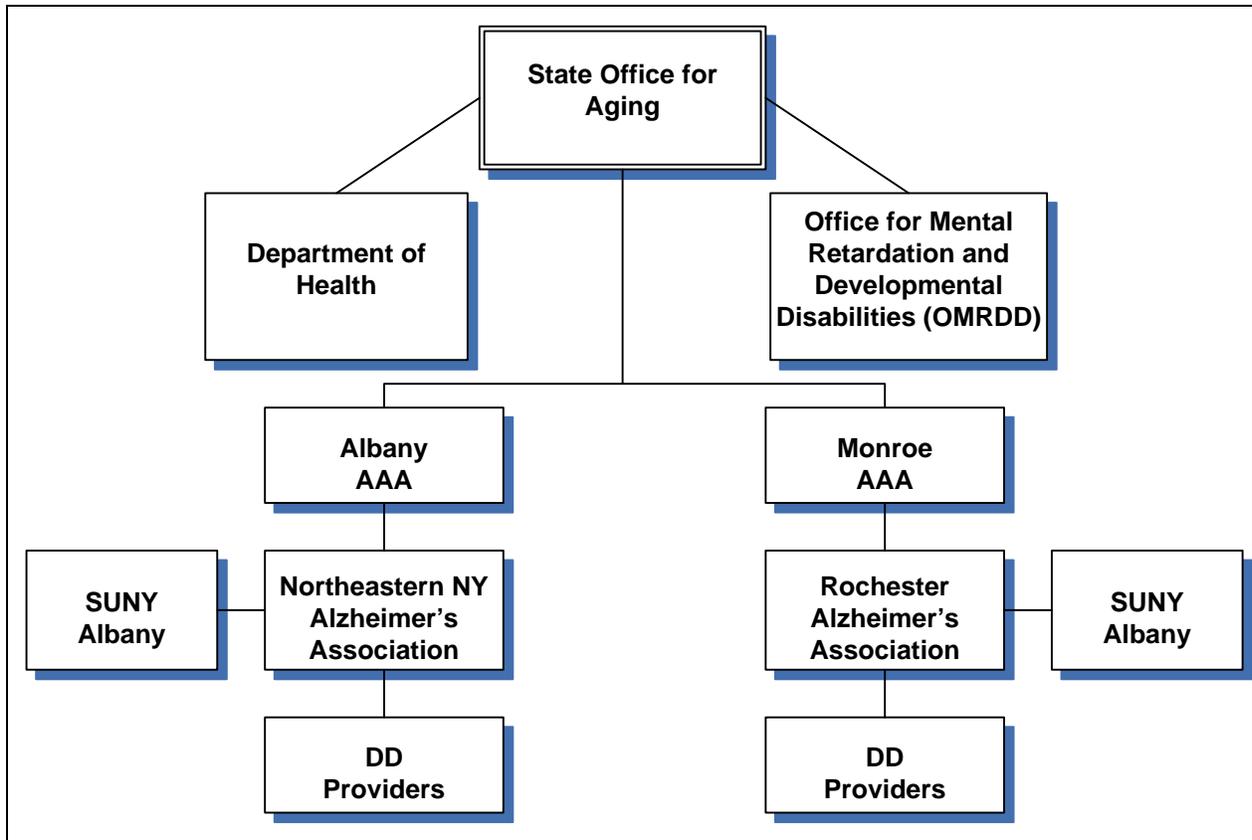
<sup>3</sup> The stakeholders included: Rochester area developmental disabilities and aging providers, the Golisano Foundation (a local foundation supporting programs for individuals with developmental disabilities), and Developmental Disability Service Organization (DDSO) staff in two communities (the Finger Lakes and Central New York regions).

The NYSOFA provided grant funds from the state to two Area Agencies on Aging which then subcontracted with two Alzheimer’s Association chapters. These chapters provided education and training and subcontracted with long-term care providers for dementia-appropriate direct services. Additionally, each chapter used funds to support a local impact evaluation.

**Grant Partners**

The primary partners for the grant are list on **Exhibit 3** and described below.

**Exhibit 3. Organizational Flow of First ADDGS Grant**



**Bureau of Chronic Disease Services within the New York Department of Health**

As requested by the Governor, the State Department of Health (DOH) provided the federally-required state match funding and assisted with initial grant implementation. Additionally, DOH provided NYSOFA with the names of local community service providers with relevant expertise. Often, these providers were already collaborating with the Area Agencies on Aging.

**Office for Mental Retardation and Developmental Disabilities**

The State Office of Mental Retardation and Developmental Disabilities (OMRDD) and its regional offices provided input in the planning process and supported grant initiatives. Across

the state, OMRDD oversees the funding options, availability, and coordination of services for individuals with developmental disabilities. The state is divided into 13 regions, and each region has a Developmental Disabilities Service Office (DDSO) responsible for monitoring and evaluating Medicaid services provided by day programs/workshops and residences to individuals with developmental disabilities. A regional OMRDD/DDSO staff person was assigned to provide technical assistance to the grant stakeholders who were not as familiar with how the OMRDD system operates.

**The Albany County Office for the Aging and Monroe County Department of Health and Human Services, the Area Agencies on Aging in Albany and Monroe Counties, Respectively**

The role of the Area Agencies on Aging was largely administrative. Each agency served as the funding mechanism for education, training, and direct services to persons with developmental disabilities and Alzheimer's disease, providers, and community caregivers, and monitored the contract with the Alzheimer's Association chapters. As stated above, each agency funded its local Alzheimer's Association chapter to provide dementia-specific education and training to community caregivers and Area Agency on Aging, developmental disabilities, and long-term care service provider staff and to broker services to meet dementia care needs of the participants.<sup>4</sup> The agencies provided lists of existing long-term care service providers and contract templates to the Alzheimer's Association chapters.

**Northeastern NY Alzheimer's Association Chapter (covering Albany County) and the Rochester Alzheimer's Association Chapter (covering Monroe County)**

The chapters secured contracts with direct services providers. The Alzheimer's Association chapter in each region<sup>5</sup> managed the project at the local level by:

- identifying participants;
- developing care plans to address Alzheimer's disease-related needs;
- coordinating direct services;
- providing training to direct care staff working at community residences and day programs, and family members and group home caregivers;
- monitoring program effectiveness at the local level; and
- providing support groups for staff at group homes and family caregivers by recruiting facilitators and training them (Alzheimer's Association Fact Sheet, 2004).

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<sup>4</sup> The role of the Alzheimer's Association chapter as a service broker was to assist families and individuals to make informed decisions about what will work best for them, identify providers of the services, and ensure that the service is in fact provided to the individual or family.

<sup>5</sup> During the grant, both the Rochester and the Northeastern New York chapters of the Alzheimer's Association provided services to individuals in nine counties in their respective regions.

## **Developmental Disabilities Service Provider Network**

The providers targeted for this grant included social and medical adult day care centers and vocational work and sheltered workshop sites (hereinafter known as day programs), and caregivers of persons with developmental disabilities and Alzheimer's disease regardless of community arrangement (e.g., group home and adult foster care). These providers are primarily funded through the Medicaid home and community-based services waiver within the OMRDD system. For this grant, the role of providers was to provide staff to participate in training from the Alzheimer's Association, identify and refer potential service beneficiaries, and make changes to programming or the physical space to address Alzheimer's disease-related needs.

## **The State University at Albany's Center for Excellence in Aging Services**

Each Alzheimer's Association chapter hired the State University at Albany's Center for Excellence in Aging Services (hereinafter known as the SUNY evaluators) to provide the Alzheimer's Association chapters with assistance in the initial stages of grant implementation, help conduct trainings, and conduct the evaluation of both sites.

The SUNY evaluators analyzed quantitative information regarding the impact of services on caregiver stress (through questionnaires with caregivers) and the qualitative results of focus groups regarding the perceived impact of the demonstration project. They also examined perspectives of agency administrators, the impact of the delivery of training and services, environmental modification, and end-of-life issues. Their findings are summarized in a final grant report, "New York State Coordinated Care Alzheimer's Demonstration Project Evaluation" (Nickle and McCallion, 2005).

## **Grant Strategies and Activities to Provide Services**

In order for NYSOFA to achieve project goals, grant staff implemented several strategies. The following subsection describes efforts to increase access and availability of dementia-appropriate long-term care services, to develop the workforce, and to influence policy, procedures, and funding. It also presents grant stakeholders' impressions about the grant's success.

### **Enhancing Access to Dementia-Appropriate Services**

According to grant staff, enhancing access to services for individuals and families was an essential component of the success of the grant to individuals and families.

### **Grant Partner Role and Activities**

To improve access to dementia-appropriate services, the Alzheimer's Association chapters in each county trained developmental disabilities providers and family members to recognize the symptoms of dementia, securing a diagnosis of dementia, identifying needs, assessing the levels of need, creating plans of care, and making referrals for services in coordination with the chapter's subcontracted direct service providers.

Several developmental disabilities provider sites also implemented dementia screening programs for persons with developmental disabilities. For example, one day program provider

reported that the Alzheimer’s Association chapter helped develop a new dementia screening process for beneficiaries that became mandatory for participants age 40 and older.

In addition to utilizing local resources, as necessary, grant partners made referrals to the regionally-based Alzheimer’s Disease Assistance Centers (ADACs) to obtain diagnoses of the disease—an eligibility requirement for gaining access to services and supports. Funded by DOH, the nine statewide ADACs provide diagnostic and consultative services to primary care providers in making initial assessment of patients, including the development of comprehensive care plans, assistance with the management of complex patient situations, and referrals of patients to specialty care (New York State Department of Health Web page, no date).<sup>6</sup> Ultimately, based on the low numbers of grant participants who received services from the ADACs and lack of formal diagnostic work-ups among grant participants, the SUNY evaluators recommended identifying funding mechanisms to increase the number of formal work-ups and to develop the capacity for assessments.

As much as possible, grant services wrapped around existing Medicaid- or state-funded services. For example, in an instance where an individual was already receiving evening personal care assistance through the Medicaid Home and Community-Based Services Waiver, the grant funded morning personal care assistance services to ensure that a participant could attend a day program. This additional time allowed the individual to remain in a community residence and day program.

### **Partners’ Perceptions of the Impact of the ADDGS Grant**

Stakeholders reported limited access to services and education for persons with developmental disabilities and Alzheimer’s disease and their families before the grant. The limitations existed, in part, because providers and informal caregivers were not familiar with the symptoms of Alzheimer’s disease and did not know how to reach beyond the developmental disabilities network (and traditional OMRDD resources) to the aging network for services and training, or whether such resources were even available.

One of the Alzheimer’s Association chapters remarked that the families caring for persons with developmental disabilities form a tight-knit community where families support each other, requiring the chapter to work especially hard to build the trust of the families to accept information on Alzheimer’s disease. A developmental disabilities provider noted that family members and group home operators were reluctant to admit that persons in their care had the disease because of the potential stigma.

Additionally, because of the grant, both of the participating Alzheimer’s Association chapters gained experience in developing direct services plans, managing and budgeting supportive services, and providing case management for these services. This expanded role was beyond the Alzheimer’s Association traditional role of providing consumer and caregiver education, training, and support groups.

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<sup>6</sup> For more information see [http://www.health.state.ny.us/diseases/conditions/dementia/alzheimer/about\\_adac.htm](http://www.health.state.ny.us/diseases/conditions/dementia/alzheimer/about_adac.htm).

One developmental disabilities provider at a day program reported that before the grant it did not have staff trained to recognize the symptoms of Alzheimer's disease or physical space able to accommodate persons with Alzheimer's disease, forcing it to make difficult choices about whether or not to discharge a participant. This same provider was grateful that the grant gave the organization the ability to continue to serve individuals known to staff, in many cases for over a decade.

One of the Area Agencies on Aging noted that it did not have programs targeted to the aging developmental disabilities population until the grant. This agency did not routinely identify needs or process requests for aging services from the developmental disabilities population. After the grant was implemented, however, the agency began to inform family caregivers and other caregivers about the services available and the benefits of the services. The agency felt that the grant resulted in caregivers having an increased awareness of available supports and services, including congregate and home-delivered meals, home care, and companion services.

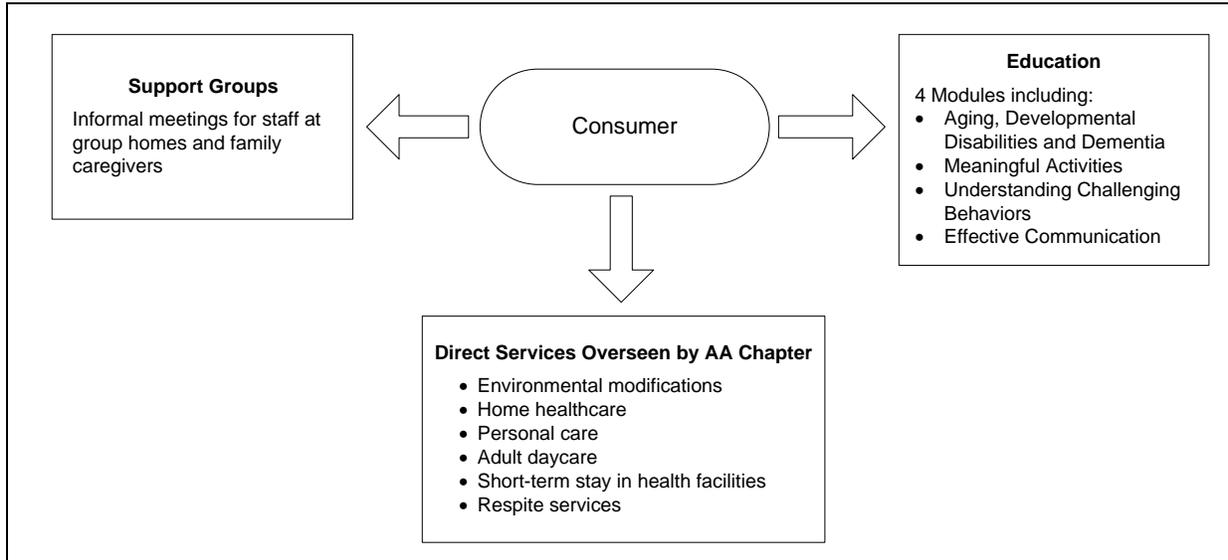
This same Area Agency on Aging also noted that, as a result of the grant, the agency received matching funds from the DOH to provide services to individuals age 50 and up. Typically, Area Agencies on Aging only provide services to individuals age 60 and older because of the requirements of the Older Americans Act (although the ADDGS program does not have this age limitation). And finally, the Area Agency on Aging reported that many of its case managers began to see the long-term care community as one that includes seniors and younger adults.

### **Enhancing the Availability and Quality of Services**

The ADDGS provided staffing, personal care assistance, and environmental modification to persons with developmental disabilities and Alzheimer's disease as well as their family members. The chapters handled care consultation and arranged for services between the individual/family member and the following types of services: home health care, transportation, respite, personal care, adult day care, companion services, short-term care in health facilities and other respite settings, and environmental modifications. Using grant funding, the Alzheimer's Association chapters also provided directly or subcontracted for environmental assessments and provided adaptive tools to promote independence. The chapters also facilitated discussion and established support groups for consumers at residential and day sites. **Exhibit 4** shows the Rochester Alzheimer's Association chapter's program model.

Over the 3-year period, 177 individuals received grant services at a cost of approximately \$5,000 per individual per year. Of the 177 participants, 21 individuals (approximately 12 percent of the total) required a change in residential placement, 7 individuals moved from a residential setting to a skill nursing facility, and the remaining individuals remained in the same place but required a higher level of care (Nickle and McCallion, 2005).

## Exhibit 4. ADDGS Coordinated Care Grant: Rochester Alzheimer's Association Services for Participants



SOURCE: Monroe Area Agency on Aging, 2006, based on internal Area Agency on Aging documents.

### Separate Dementia Programming

In close consultation from the Alzheimer's Association chapter staff, both developmental disabilities day programs interviewed established separate dementia program areas. One day program noted that instead of moving clients from room to room (as was done previously), staff rotated through the dementia program area during the day to reduce clients' disorientation. Before the grant, if behavioral problems developed, the person could not remain with the general developmental disabilities population and was considered at high risk for discharge. To address these problems, the programs used environmental modifications to change their physical space and provided staff training. The programs reported the staff's sense of relief and comfort knowing that these individuals could now remain at the center safely and engaged in activities. One of the recommendations of the SUNY evaluation was increasing coordination between residential and day sites.

The SUNY evaluators indicated that DDSO Medicaid service coordinators helped the Alzheimer's Association implement the services and recommendations from the dementia-specific care plans into the larger care planning process that guides Medicaid funding of developmental disabilities providers. However, the evaluators saw a need for a more systematic approach to ensure that dementia-related recommendations were included in care plans.

### Environmental Modifications

As the grant progressed, it became evident to the partners that physical changes at day programs and residential settings augmented other direct services to ensure the persons with Alzheimer's disease and developmental disabilities could successfully age in place (Nickle and McCallion, 2005). NYSOFA did not originally include environmental modifications as part of

the grant; however, the U.S. Administration on Aging later approved these changes either in residential or facility settings (e.g., day programs). The types of changes included lowering ceilings (to diminish room noise), carpeting floors, using neutral paints (to decrease visual stimulation), renovating bathrooms, creating parlor spaces and Snoezelen rooms,<sup>7</sup> and establishing gardens and wandering paths (Harazin and McCallion, 2005).

One of the Alzheimer's Association chapters remarked on the importance of a support environment stating that, "If you bring someone with dementia home who cannot walk and cannot move around their environment independently, it does not matter who you bring in to help. They are not going to be able to thrive in the environment, regardless of staff training and the number of available staff."

The SUNY evaluation noted the environmental modifications made to day programs improved staff effectiveness and client engagement (Nickle and McCallion, 2005). The findings reiterated that the project was successful in improving programming, reducing stress on individuals with Alzheimer's disease and developmental disabilities and the staff who work with them, and maintaining the person at risk for discharge. However, researchers found that the staff ratings of likelihood of discharge did not always reflect what actually occurred (Nickle and McCallion, 2005).

### **Enhancing the Quality and Availability of a Competent Workforce**

To support family members and staff in their work with this population, the Alzheimer's Association, SUNY, and other partners (i.e., physicians or environmental modifications specialists) provided education and training on a range of topics related to working with individuals with Alzheimer's disease (described below). SUNY did not track referrals, but the grant partners believed this increased knowledge translated into more referrals. Separate from the grant, SUNY evaluators also conducted trainings for the DDSO Medicaid service coordinators on Alzheimer's disease, the disease progression, and effective methods of working with individuals who have Alzheimer's disease.

Depending on who was in attendance, the trainings were often co-led by the Alzheimer's Association and SUNY or another specialist (e.g., a physician or environmental modifications specialist from the University of Rochester Program in Aging & Developmental Disabilities within the Strong Center for Developmental Disabilities). Individuals receiving training included agency directors, administrative support staff, group home managers and staff, service coordinators, psychologists, psychiatrists, social workers, and family members. To facilitate ongoing training at the provider level, the trainers used train-the-trainer modules. Trainings often occurred at day programs (e.g., day habilitation programs) and at residential sites (e.g., group homes) to maximize participation.

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<sup>7</sup> Snoezelen is derived from the words "snuffeln" (to sniff, to snuffle) and "doezelen" (to doze, to snooze). This treatment was developed in the Netherlands in the 1970s by facilities caring for severely disabled people. A Snoezelen room is designed to use light and sound to create a relaxing and activating effect. The specific design directs and arranges the stimuli; it creates interest, brings back memories, and guides relationships. A Snoezelen room is intended to induce well-being, diminish fear, and increase an individual's sense of security (International Snoezelen Association Web site, 2006) <http://www.isna.de/index2e.html>.

In Rochester, the Alzheimer's Association chapter trained more than 800 caregivers across four key education areas including aging, intellectual disability, and dementia; effective communication; understanding behaviors; and meaningful activities. In Albany, the Alzheimer's Association chapter targeted training on dementia services and resources to different audiences including agency directors, managers, direct care staff (e.g., certified nursing assistants), and families. Over 500 direct care staff and 100 administrators received training in:

- project awareness,
- risk factors,
- dementia assessment,
- disease symptoms and progression,
- communication,
- responses to problem behaviors,
- recreation and activity planning, and
- environmental modifications.

In partnership with the New York State Developmental Disabilities Planning Council, grant staff from SUNY developed and disseminated a tool kit to train staff (e.g., direct care and professional staff in residential and day programs) to support people with developmental disabilities to live as independently as possible. The two-compact-disc tool kit is available to agencies across the state to supplement staff training (**Exhibit 5**).

### Exhibit 5. Components of the Staff Training Tool Kit

- **A video and CD-ROM**, “Dementia and People with Intellectual Disabilities: What Can We Do?”
- **A two CD-ROM self-instructional** in-service and education kit
- **Fact sheets and other informational sheets** issued by Alzheimer Disease International, The ARC of the United States, the Alzheimer’s Association, the University at Albany, the University of Illinois at Chicago, and the International Association for the Scientific Study of Intellectual Disabilities
- **The Edinburgh Principles** for community care of adults with intellectual disabilities affected by dementia
- A 20-item **Quiz on Intellectual Disabilities and Dementia**
- **A Web-based bibliography** on Alzheimer’s disease and intellectual disabilities and a hard copy of a bibliography from the Greenfield Library at the Alzheimer’s Association
- **Websites** on Alzheimer’s disease and Intellectual Disabilities
- **Protocol for recording baseline information** on behaviors of adults with intellectual disabilities (Harazin and McCallion, 2005)

SOURCE: SUNY Albany Center for Excellence in Aging Services,  
<http://www.albany.edu/aging/IDD/documents/AOAPresentation.pdf>

The SUNY evaluation reported that caregivers commented that the trainings (and the project overall) had made a positive difference in their lives and the lives of the individuals with Alzheimer’s disease and developmental disabilities. Caregivers reported less perceived difficulty in caregiving with corresponding improvement in dementia symptoms, reduced time spent caregiving, and less burnout (Nickle and McCallion, 2005). The evaluators reported that the trainings made a difference in the quality, confidence, morale, and competence of direct care workers. In focus groups, these individuals reported greater awareness of the signs/symptoms of dementia, and how to more effectively interact and communicate with individuals and family members.

To determine the impact of the training and services supported by the grant, SUNY staff randomly selected 69 grant project participants in both regions (encompassing 8 counties) and interviewed caregivers on two occasions (6 months apart) concerning the participants in their care. SUNY administered two interview instruments and a survey regarding the project participant. The evaluation presented three statistically significant primary findings: (1) caregivers reported less perceived difficulty/burden in caregiving with no corresponding improvements in ADD symptoms; (2) the grant services (and supports) provided a reduction in behavior perceived as difficult (yelling, swearing, wandering, confusion, assisting with exercises, daytime supervision, not having knowledge/training in dementia care, and conflicts on care needs); and (3) caregivers noted that the grant had made a positive difference in their lives and the lives of the individual (Nickle and McCallion, 2005, p. 19).

## **Influencing State and Local Policies, Procedures, and Funding for Services**

The State Office on Aging believed that using the lessons learned from the grant to help shape state and local policies, procedures, and funding for services for individuals with developmental disabilities, Alzheimer's disease, and other dementias was a key component of the grant. The State led the dissemination of information about the grant to other communities to encourage local Alzheimer's Association, developmental disabilities provider, and caregiver networks to work collaboratively.

Grant partners recognized changes in state care planning requirements which allowed persons with developmental disabilities and Alzheimer's disease to remain at day programs with Medicaid funding, essentially allowing them to age in place. Additionally, several grant partners leveraged their participation in the grant to receive additional grants from the state and foundations in order to continue serving persons with developmental disabilities and Alzheimer's disease and their caregivers.

### **Dissemination**

Grant partners had the opportunity to successfully disseminate information in several forums, including two conferences sponsored by NYSOFA and the Alzheimer's Association at the conclusion of the grant. The two conferences were attended by more than 100 professionals from day programs, Area Agencies on Aging, Alzheimer's Association chapters, and State agencies at each. Additionally, in spring 2006 NYSARC, Inc.<sup>8</sup> invited the state grant project director and the lead SUNY evaluator to present at a symposium which highlighted grant efforts and outcomes; they also briefed the Governor's and OMRDD and DOH staff on several occasions.

The dissemination conferences energized local discussion and planning efforts. NYSOFA reported that many counties have requested trainings and materials and at least 10 counties have offered training on assessments in the post-grant period. Several of the individual ARCs in the state have contracted with SUNY for technical assistance. The NYSARC Association implemented a special conference specifically on aging in spring 2006 (as mentioned above); also, NYSARC developed a strategic plan on aging and has several regional committees working on this topic. Additionally, OMRDD convened a Commissioner's Advisory Council on Aging to provide input on program design and NYSOFA is participating on this council.

### **Partner Relations**

Overall, grant partners felt that the stronger relationships between Alzheimer's Association staff, OMRDD regional staff, developmental disabilities and long-term care service providers, and Area Agency on Aging staff resulted in increased access for persons with developmental disabilities and Alzheimer's disease to services, supports, and training. All partners reported that after the grant was implemented, the relationships with other participating

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<sup>8</sup> NYSARC is a statewide advocacy organization for individuals with developmental disabilities that provides early intervention, health care, education, preparation for employment, help in finding and keeping a job, independent living, skill training, leisure and recreation activities and spirituality (NYSARC Web site, no date, <http://www.nysarc.org/family/nysarc-family-association-chapter-services.asp>).

providers was strengthened. Partners commented that the interest and availability of other partners was an asset; staff reported that they could call any of the providers and receive answers to their questions in a timely manner. Additionally, with the implementation of the grant, relations between the aging and developmental disability network improved. Each was viewed by the other as a viable and contributing community partner. Even so, the SUNY evaluation recommended more joint planning and program development between the aging, health, and developmental disabilities service sectors.

### **Policies and Procedures**

One important result of the grant's influence on state policies and procedures was approval of the OMRDD sanctioned care plans that allowed the participants with developmental disabilities and Alzheimer's disease in day programs and adult day sites to remain at the same location with Medicaid funding as their disease progressed. The OMRDD, and subsequently the DDSOs, generally require that all individuals improve/increase their level of functioning annually in order to qualify for and receive ongoing funding.

Several providers in the developmental disabilities network recognized through their participation in the grant that this philosophy was not appropriate for individuals with developmental disabilities and Alzheimer's disease as they were not capable of making functional improvements. Grant partners successfully advocated to the local DDSOs that instead of skill acquisition, skill maintenance and support for decline was a more appropriate approach for this population. The OMRDD changed its policies for both regions involved in the grant to approve care plans that promoted maintenance of activities and quality of life instead of improved skills for individuals with developmental disabilities and Alzheimer's disease. (NYSOFA reported that other regions in the state have implemented a similar policy but does not have definitive information.) Thus, for example, the goal for an individual to make eye contact to acknowledge a friend was now approved, whereas before the onset of the Alzheimer's disease, the individual's goal was to regularly converse with others. Making eye contact was considered a success because the individual participated in the activity to the best of his or her ability.

Another example of the skill maintenance/support for decline was the decision by OMRDD to allow day programs to provide a daybed for individuals to take naps. Previously, day programs were not allowed to have beds available to clients, as sleeping was not considered a productive activity. However, once day program staff and state case managers at OMRDD better understood that taking naps was therapeutic and helps maintain skills, the agency approved day beds and allowed naps if there was a note from a physician. Often, staff placed the daybeds in the Snoezelen rooms.

The grant also influenced other grant partners at the agency level. Because of the success in working with the developmental disabilities population through this grant, the Albany County Area Agency on Aging decided to include persons with mental retardation/developmental disabilities and persons with mental illness into the population served by the point-of-entry long-term care system that is being developed. Including these populations was not a state requirement under the NYANSWERS initiative, but the Area Agency on Aging felt that all persons with disabilities should be included in the system, rather than just individuals over 65.

## **Funding**

The Alzheimer's Association chapters have tried to sustain care consultation, direct services, and training for persons with developmental disabilities and Alzheimer's disease by leveraging other funding sources or absorbing costs into existing budgets. The developmental disabilities providers remain committed to training their own staff, seeking dementia-appropriate services for their clients, and implementing environmental modifications and other life enrichment services (e.g., memory and sensory adaptations).

The trainings developed by both Alzheimer's Associations for families and staff are now a component of their training repertoires and available to interested agencies or individuals. The Rochester Alzheimer's Association chapter also received grant funding from OMRDD to continue dementia support services. The ADDGS grant essentially served as a pilot for the subsequent grant which allowed the Alzheimer's Association to sustain many of the ADDGS grant services. The New York State-Options for People Through Services (NYS-OPTS) grant program funds the follow-on grant, which requires projects to focus on building person-centered services in the areas of employment, transitional services, community inclusion in social activities, independent living skills and educational opportunities (Commission on Quality of Care Web page, 2005). With the \$5 million OPTS grant, the Alzheimer's Association is providing care consultation, discussion groups (formerly referred to as support groups), education for providers and family caregivers, and life enrichment (e.g., environmental modifications, transportation, and respite).

The same day program providers mentioned above have also sought additional funding from state and community foundations. For example, the Monroe County ARC, which runs a day program, received two small grants from a local foundation to create a music and exercise program and additional money for further environmental modifications, totaling over \$100,000.

### SECTION 3 POINT-OF-ENTRY GRANT (JULY 1, 2005–JUNE 30, 2008)

In July 2005, the New York State Office on Aging (NYSOFA) began implementing the second Alzheimer’s Disease Demonstration Grants to States (ADDGS) grant, which is designed to create a dementia-capable single point of entry (POE) that utilizes a county-based long-term care central assessment system and works effectively with existing state-funded Alzheimer’s disease screening and service delivery system in rural areas and ethnically diverse small cities (McCallion and Harazin, 2005; New York ADDGS Project Summary, 2006). Through the grant, two counties integrated dementia services, education, and training to the existing Area Agency on Aging-based POE system. Previously, an individual with Alzheimer’s disease or family-member requesting supports or services would have received fragmented care and been referred to the Alzheimer’s Association for Alzheimer’s disease-related assistance. Within the newly integrated system, the Alzheimer’s Association staff and Area Agency on Aging case manager provide information and access to a full range of services related to long-term care.

Individuals living in rural areas and persons who are ethnically diverse and living in small cities are of particular concern to NYSOFA officials because few services and supports are currently available to them. Additionally, some services available to individuals in large urban areas are not necessarily available to those individuals residing in small cities or rural areas (McCallion and Harazin, 2005). NYSOFA’s primary criteria for selecting the two counties to pilot this initiative were that the counties have a high concentration of rural and ethnically diverse communities and have exhibited a commitment to and demonstrated progress toward meeting the goals of the NYANSWERS initiative. In 2004, the Governor established the Access New York Service With Effective Responsive Supports (NYANSWERS); it is designed to change the design and delivery of state, private, and publicly funded long-term care programs. The intent is to create a point of entry system offering long-term care including screening, information, assistance, assessments, and access to public and private community based care (McCallion and Harazin, 2005).

In the first year of the second grant, the grant partners in both counties developed the policies and procedures that facilitated the inclusion of persons with Alzheimer’s disease into the existing POE systems and began providing direct services to this population. In the spring of 2006, both counties began serving clients<sup>9</sup> and providing trainings to agency administrators, direct care staff, caregivers, and grant service providers. As of June 30, 2006, the two POEs received a combined 80 referrals and deemed 27 individuals eligible to receive services.<sup>10</sup> **Exhibit 6** presents the key objectives of the Point-of-Entry grant. Efforts in the second and third years of the grant are focused on increasing referrals of persons with Alzheimer’s disease residing in rural and ethnically diverse communities and attracting primary care physicians and

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<sup>9</sup> As of June 30, 2006, services have included home health care (personal care and respite), referrals to both social and medical model adult day care, companion services, transportation, enrollment in the Safe Return program, the purchase of a “Med Ready” pill box, and environmental modifications.

<sup>10</sup> The grantee anticipated enrolling 40 individuals with Alzheimer’s disease during the first year and 80 individuals in each of the second and third years; these numbers are combined totals for both counties.

other medical staff to trainings on dementia and to increase their level of referrals to the POE system.

### **Exhibit 6. Key Objectives of New York’s ADDGS Point of Entry Grant**

- Increase access to dementia-appropriate long-term care services for persons with Alzheimer’s disease and other dementias by creating a dementia-capable point-of-entry and service delivery system supported by Area Agencies on Aging, Alzheimer’s Association chapters, and Alzheimer’s Disease Assistance Centers (ADACs are described on page 11).
- Enhance the availability and quality of direct services for persons with Alzheimer’s disease and other dementias and for family caregivers by contracting with a well-known dementia care and advocacy organization to subcontract with providers to offer dementia-appropriate services and to coordinate services between the providers and clients.
- Meet the needs of persons with Alzheimer’s disease and their family caregivers in rural and small ethnically diverse cities by hiring a dementia-specific case manager to manage and deliver all diagnostic and direct care services.
- Establish a competent workforce for those caring for persons with Alzheimer’s disease and other dementias by connecting families and long-term care service providers with dementia-specific training, providing informational and educational materials, serving as a portal to access community resources, information, and other long-term care service options.
- Disseminate the POE services model, trainings, and examples of systems change to other regions in the state.
- Leverage ADDGS funds to sustain the program after grant funding ends.

### **Background**

The NYANSWERS statewide initiative directs counties to create a POE system for long-term care consumer access. The POE system provides consumers with impartial screening, information, assistance, assessment, and access to appropriate and timely public and private community-based care options. Similar in philosophy to the U.S. Administration on Aging’s Choices for Independence initiative, the approach of the POE is to support self-determination, promote personal responsibility, and provide needed services that are both high quality and efficient.<sup>11</sup>

In advance of the mandatory statewide implementation of the POE effort, NYSOFA and the SUNY Albany Center for Excellence in Aging Services applied for an ADDGS grant. The purpose of this grant is to enable New York State to integrate services for persons with

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<sup>11</sup> For more information on Choices for Independence, see:  
[http://www.aoa.gov/about/legbudg/oa/Selected\\_Provision\\_For\\_Choices.doc](http://www.aoa.gov/about/legbudg/oa/Selected_Provision_For_Choices.doc).

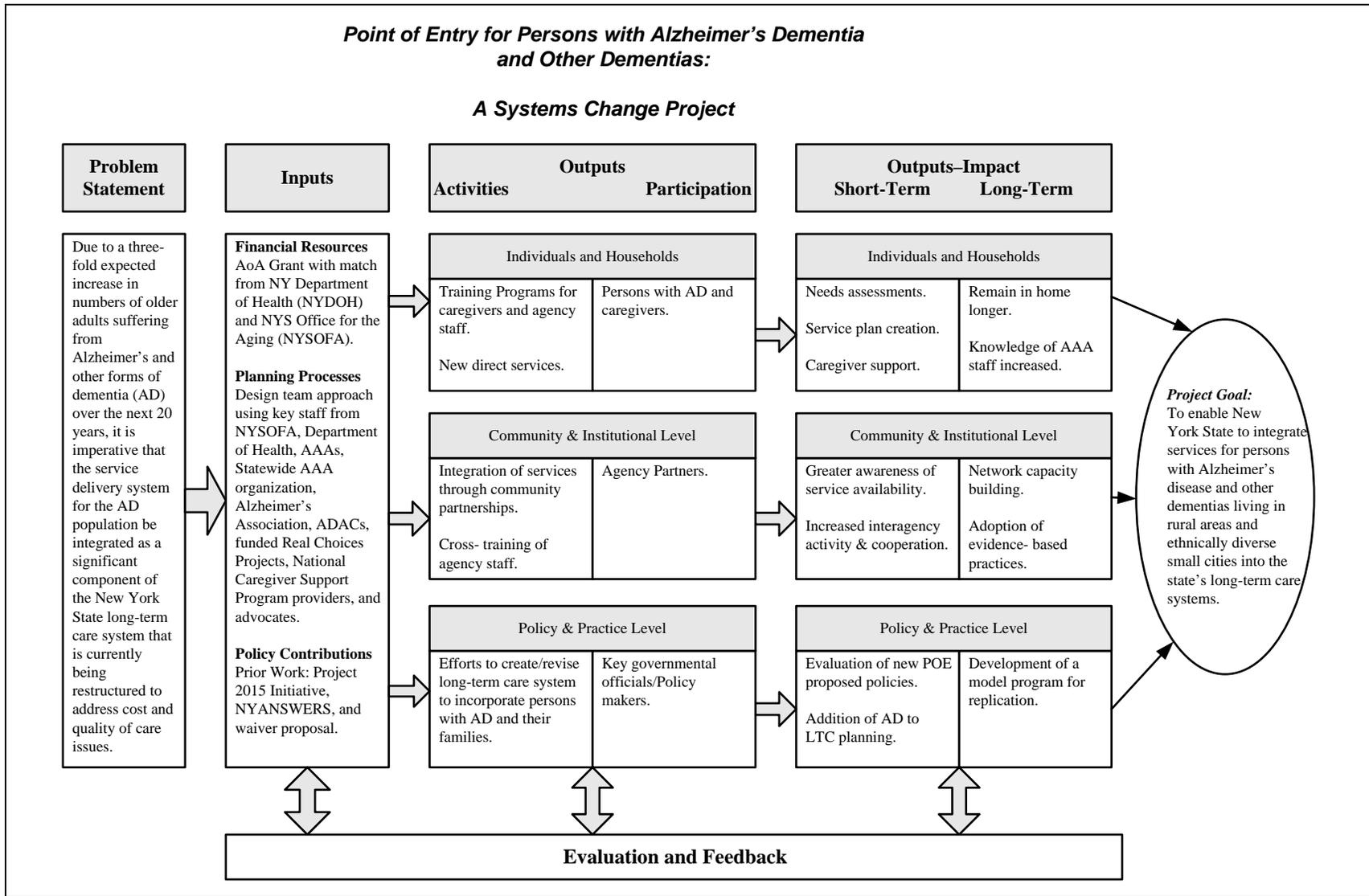
Alzheimer's disease living in rural areas and ethnically diverse small towns into the county-based long-term care central assessment programs and to integrate services offered by Area Agencies on Aging, Alzheimer's Association chapters, and ADACs. Both counties selected for the ADDGS grant had established, mature POE systems in place. The grant funding supported the addition of a staff with dementia expertise and familiarity with dementia services to the POE. As depicted in **Exhibit 7**, the intent of the project is to integrate services offered by Area Agencies on Aging, Alzheimer's Association chapters, and ADACs in areas where a large number of rural and ethnically diverse residents resided. Furthermore, grant services are designed to wrap around existing Medicaid and state-funded services and intended to be the payer of last resort for all services.

NYSOFA targeted individuals with Alzheimer's disease living in rural areas and ethnically diverse individuals with Alzheimer's disease and their families under this grant because neither group is highly integrated into the long-term care continuum and few services or supports are in place to assist them (McCallion and Harazin, 2005, p. 3). Focus groups conducted with Area Agency on Aging and adult protective services staff by SUNY prior to the start of the grant found that while increased services and family supports are critical to maintain individuals with Alzheimer's disease in the community, lack of assessment, lack of services, and poorly coordinated services and supports increase the likelihood of these individuals requiring institutionalization (McCallion, 2004). Furthermore, state initiatives designed to provide services to individuals with Alzheimer's disease are implemented in large urban areas, the same services and initiatives are not necessary adaptable to smaller towns (McCallion and Harazin, 2005, p. 3.). An increasing number of aging and ethnically diverse individuals are moving into small towns and cities; thereby reinforcing the importance of and need for an integrated POE that includes Alzheimer's disease-related assistance.

According to the 2000 census, nearly 16 percent of New Yorkers are African American; 6 percent are Asian; 15 percent are Hispanic and more than 10 percent identify themselves as either multiracial or another race (U.S. Census Bureau, 2000a). In terms of urbanization, in 2000, approximately 13 percent of all residents live in rural areas where accessing health care can be challenging (U.S. Census Bureau, 2000b). Of the 62 counties in the state, 44 are rural (New York State Office for the Aging, 2004). Because of these data, the state recognized the importance of developing policies to address the needs these individuals in its POE design.

As with the Coordinated Care grant, the current ADDGS grant is led by the New York State Office on Aging. Also similar to the first grant, NYSOFA provided funding to the Area Agencies on Aging. These agencies subcontracted with the local Alzheimer's chapters which in turn subcontracted with long-term care providers.

### Exhibit 7. Point of Entry Flow Chart

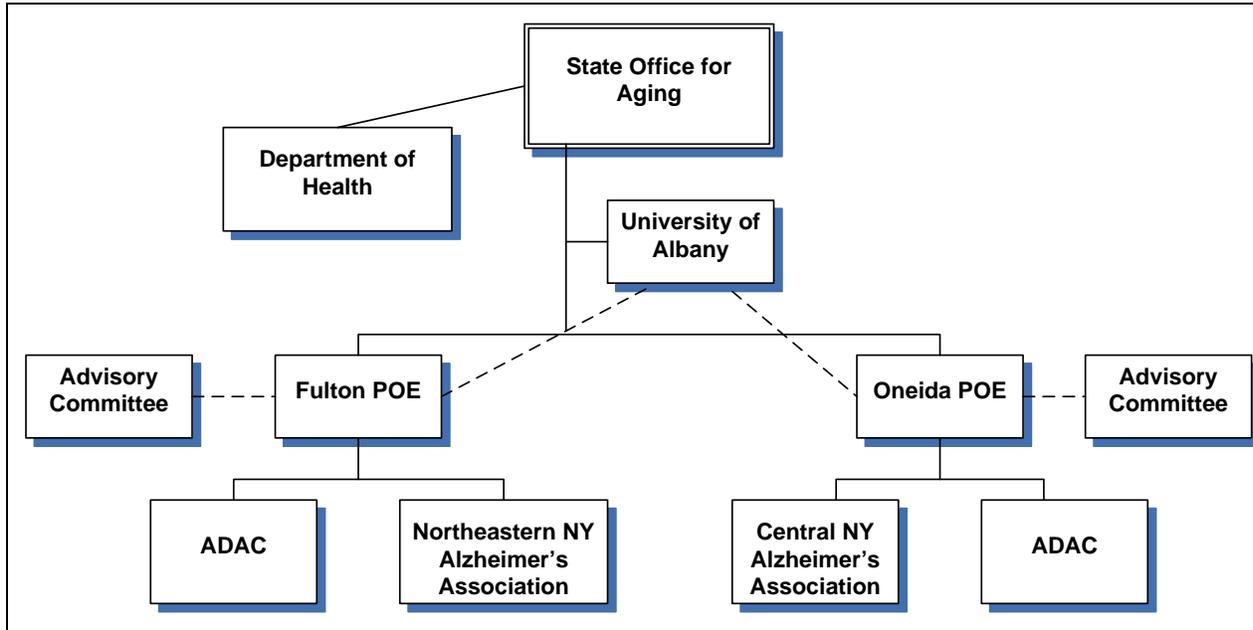


SOURCE: New York State Office for the Aging, 2006.

## Grant Partners

The primary partners for the grant were the following organizations portrayed in **Exhibit 8** and described below.

**Exhibit 8. Key Partners of the Point of Entry Grant**



### **Bureau of Chronic Disease Services within the New York Department of Health**

Similar to the first ADDGS grant, the Department of Health provided the grant's state match funding. Additionally, DOH assists with the dissemination of grant information; for example, DOH hosted an Alzheimer's disease conference in June 2006 and invited NYSOFA staff to present.

### **The Area Agencies on Aging in Fulton and Oneida County, respectively the Fulton County Office for the Aging and the Oneida County Office for the Aging**

In both counties, the Area Agency on Aging administers the POE and works with Alzheimer's Association chapters and ADACs to provide services. At the agency level, managers and case manager supervisors developed the structure for how to handle referrals for persons with Alzheimer's disease, utilizing the knowledge of the Alzheimer's Association and integrating the referrals into the existing POE system. Case managers are responsible for working closely with Alzheimer's Association grant staff to handle the referrals and to assess the needs of individuals with Alzheimer's disease, develop a services plan, and arrange for caregiver supports. In some counties, case managers at Area Agencies on Aging are partially funded by Medicaid; across the state, case managers are trained in Medicaid home and community-based services waivers and state plan services, and private pay service options.

## **Northeastern NY Alzheimer's Association Chapter (covering Fulton County) and the Central New York Chapter (covering Oneida County)**

The Alzheimer's Association grant staff are responsible for providing care consultation to the POE system case managers, for training staff (e.g., agency case managers and service provider management and staff) and brokering direct services to individuals.

### **Alzheimer's Disease Assistance Centers**

The regional ADACs serve as a community resource for individuals with Alzheimer's disease and their family members and, as necessary, provide diagnosis and assessment services. The ADACs also provide patient management and care, training, education, and consultation, and serve as a clearinghouse of Alzheimer's disease information. Securing a diagnosis is needed in order to facilitate the delivery of long-term care services, including grant-funded services.

### **Grant Advisory Committees**

In each county, the work of the key partners is supported by a local advisory committee composed of representatives of aging and dementia services, long-term care, the medical community, local government, and other community agencies. The role of the committee is to provide the following:

- information on the status of the partners and their ability to develop and sustain project goals,
- assistance in the development of work plans on key project issues, and
- ongoing support of project implementation at the local level (Harazin and McCallion, 2005).

### **The State University at Albany's Center for Excellence in Aging Services**

The Center evaluates the program and provides technical assistance and staff trainings. Thus far, technical assistance from the SUNY staff has included working with the Area Agencies on Aging, Alzheimer's Association chapters, and members of the Advisory Board on design and implementation of changes in policies and procedures; organizing the advisory board meeting plans; and designing the program logo used by one of the counties.

The program evaluation plan includes:

- collecting data on people with Alzheimer's disease identified, diagnostic work-ups completed, care plans developed and implemented, caregivers trained, individuals with Alzheimer's disease maintained in the community and associated costs;
- determining changes in service delivery that reflect a better relationship between assessment and delivery of services and the impact of case management on individuals with Alzheimer's disease or family members through interviews with stakeholders and review of case files;

- collecting data on collaborative efforts between grant partners by observing meetings and interviewing stakeholders;
- evaluating the impact of training and direct service delivery on family caregivers using pre- and post-administration caregiver burden surveys; and,
- conducting semi-structured interviews with project staff to assess expectations of the project (at initiation), ongoing experiences (on an annual basis) and satisfaction with outcomes (at the end of the project) (McCallion and Harazin, 2005).

## **Grant Strategies and Activities to Integrate Services**

As a way to achieve the primary goal of incorporating persons with Alzheimer's disease into county long-term point-of-entry systems, grant staff has begun to implement several strategies. These strategies are described below.

### **Enhancing Access to Dementia-Appropriate Services**

In order to create a dementia-capable POE that will increase access to dementia services for individuals with Alzheimer's disease and their families, each county developed a model of integrated case management and dementia services for persons with Alzheimer's disease that fit into the existing POE system. The goal is to enable rural or ethnically diverse persons or caregivers to go to one place to obtain necessary services, education, and training and centralize care planning and service delivery to individuals with Alzheimer's disease and their families, and training for the staff in aging and dementia networks.

The intent of the POE grant is to integrate dementia needs and services into other aging-related services; increasing access to services while decreasing duplication of intake information (i.e., repeating intake information to multiple staff). By providing needs assessments, care plans, and caregiver support, the knowledge of POE staff to bring resources to these individuals and their families will increase and will help persons with Alzheimer's disease live longer in the community. The grant partners plan to incorporate the expertise of the local Alzheimer's Association into the Area Agency on Aging case manager teams in order to: (1) provide training programs for caregivers and agency staff; and (2) develop new direct services for persons with Alzheimer's disease and their families. In Oneida County, the Alzheimer's Association employee (the Alzheimer's disease case manager) is located at the Area Agency on Aging as a case manager for dementia cases. The Alzheimer's Association employee is part of the intensive case management team and is responsible for managing the dementia services. In Fulton County, the Alzheimer's Association staff meet with Area Agency on Aging case managers weekly.

### **Provider Relationships**

Partners reported the grant thus far has served to strengthen and expand the relationships between the various parties. Area Agency on Aging and Alzheimer's Association staff had a prior relationship because of collaboration on the National Family Caregiver Support Program and in the case of Fulton County, the Area Agency on Aging and the Alzheimer's Association collaborated on the Coordinated Care grant. All parties appreciate the accessibility of NYSOFA and SUNY staff in developing the policy and procedures and noted the Area Agency on Aging

case management staff were an essential component of reviewing and improving the policies and procedures.

### **Enhancing the Availability and Quality of Services**

Before the provision of direct services, the Area Agencies on Aging and Alzheimer's Association chapters, in conjunction with NYSOFA staff and SUNY evaluators, spent a significant portion of the first year training staff and implementing the policies and procedures necessary to integrate Alzheimer's disease-appropriate services into the POE. Both counties began to offer direct services in the spring of 2006.

Prior to the implementation of the grant, when dementia was suspected, the Area Agency on Aging referred the individual or caregiver to the Alzheimer's Association for assistance; now, the two work together to provide services and case management. Under the grant, the Alzheimer's Association contracts with the service providers and is responsible for arranging service provision. The Alzheimer's Association is working to develop community partnerships that lead to greater awareness of service availability and to increased interagency activities and cooperation, ultimately building capacity of the aging network.

The types of services available to individuals include social adult day care, medical adult day care, transportation,<sup>12</sup> personal care assistance, home health aides, housekeeping services, companion services, respite services, case management, bill payer program, environmental modifications and representative payee assistance. As part of the training, Area Agency on Aging case managers are directed to utilize Medicaid or state-funded services prior to authorizing grant funds for these services; hence, where possible, the grant is to be used as payer of last resort and to supplement existing services.

If a dementia diagnosis exists or is expected,<sup>13</sup> the case manager develops and implements a plan for services. First, the case manager conducts a home visit and needs assessment and drafts a care plan. Second, a case conference is held with staff at the Area Agency on Aging and Alzheimer's Association to review the service plan; the case manager communicates with the family, if necessary, to obtain approval for the care plan. Third, the Alzheimer's Association brokers services with relevant providers and conducts follow-up with the client/family and providers. As reported earlier, as of June 30, 2006, 27 individuals in both counties had begun to receive grant services.

Individuals receiving services live in both rural and urban settings. Outreach to the ethnically diverse communities is a second year goal of the grant; staff want to ensure that integration of Alzheimer's disease expertise and familiarity with Alzheimer's disease services into the POE is complete prior to including this population. Representatives from these

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<sup>12</sup> In addition to transportation to and from the home and day programs, the grant also reimburses participants for transportation to and from the ADACs. Because the ADACs are located far from the grant service area, individuals cited the lack of and cost of transportation as a barrier to obtaining dementia assessments and diagnosis. Providing for transportation to the ADACs was viewed as a way to increase access to services.

<sup>13</sup> Grant staff will approve the implementation of services to individuals prior to a dementia diagnosis; however, authorization is granted with the understanding that services will be stopped if there is not a dementia diagnosis.

communities (e.g., refugee resettlement communities for immigrants from Belarus, Bosnia, and Vietnam) are members of the advisory committee and are aware of the grant progress to date.

### **Enhancing the Quality and Availability of a Competent Workforce**

The Alzheimer's Association chapters and SUNY are in the process of training a range of professionals, including Area Agency on Aging case management staff, administrators, and direct service providers, including physicians, nurses, social workers, and community members (e.g., police, transportation providers, and representatives of religious organizations). Some of the topics that have been addressed include:

- grant information including research components, service contracting and payment procedures with providers, and general outreach;
- the benefits of an active mind in relation to lowering the risk of Alzheimer's disease;
- communication strategies for providers to individuals with Alzheimer's disease;
- key principals of Alzheimer's disease; and
- cross-agency collaboration and outreach (Harazin and McCallion, 2005; New York State Office for the Aging, 2006).

The goal of the grant's training component is to reach as many people as possible who come in contact with the dementia population. In Oneida, the Area Agency on Aging Alzheimer's disease case manager travels to the provider agencies to conduct the training to encourage as many staff as possible to attend the trainings. Families have received in-home education, training, and referrals to support groups. Grant staff noted that significant time is spent learning the struggles and challenges of caregivers and providing assistance to work through them. Trainings and support groups are available and free to the attendee though not funded with grant funds.

Grant partners in both counties seek to reach local medical providers and are actively engaged in outreach to the medical community. One of the Alzheimer's Association chapters conducted a brown bag training for physicians, support staff, and community providers during which a physician in charge of a dementia unit in Albany discussed the benefits of referring individuals for services; another training will discuss hands-on care and communication for persons with Alzheimer's disease. The grant will provide scholarship funds for nurses to attend the training.

### **Influencing State and Local Policies, Procedures, and Funding for Services**

As with the first grant, the State Office for the Aging plans to disseminate information about how to integrate services for persons with Alzheimer's disease into the state's point-of-entry long-term care system, particularly in rural and ethnically diverse communities and smaller cities. This will be accomplished during the last year of the grant by conducting two regional conferences describing the lessons learned from the pilot program. SUNY will also develop a manual, which will be used to help other communities develop and implement a dementia-

capable POE. The timing of the grant is fortuitous because all counties in the State have to develop a POE system for long-term care and information from this grant will help them develop a dementia-capable POE from the outset. Finally, NYSOFA will organize meetings statewide to identify replication sites throughout the state.

### **Policies and Procedures**

Both counties report that a more intensive form of case management exists now because of the grant. Case managers assess clients, develop a care plan, refer individuals to service providers, and monitor the progress and changing needs of individuals with Alzheimer's disease and family members. Before the grant, the case manager would visit the client, develop a plan, and broker the service but not see the client again for 6 months. One case manager said this intensive case management has resulted in more time spent on identifying community resources and maximizing traditional services. Because of grant funding, the POE staff are more comfortable working with individuals with Alzheimer's disease and their caregivers; staff has adequate time to work with individuals with Alzheimer's disease and their families, educate them about the disease, and inform them of direct service options. One Area Agency on Aging reported that the weekly case conferences are a strength of the system. The brainstorming component and ready access to services are seen as a make or break point for a family in crisis.

### **Funding**

One of the grant objectives is to leverage ADDGS funds to sustain the program after funding ends. Grant partners have not yet discussed continuation funding, since the project is still in a beginning phase. The advisory councils are tasked with researching funding possibilities. Some of the possible options include:

- seeking greater Medicaid reimbursement for case management services,
- seeking funding from the national Alzheimer's Association, and
- requesting funding from local foundations.

The Oneida Area Agency on Aging intends to fund the Alzheimer's disease case manager position from general revenue after the completion of the grant. Furthermore, the Oneida Area Agency on Aging has recently received \$230,000 from the Community Elder Wellness Council which will be used in conjunction with grant funds to provide home modifications for seniors and persons with Alzheimer's disease.

## SECTION 4 CONCLUSION

### Coordinated Care Grant

The Coordinated Care grant implemented an innovative approach to provide services to persons with developmental disabilities and Alzheimer's disease and their caregivers. Grant stakeholders reported that the grant successfully created a model for providing home and community-based services to persons with both developmental disabilities and Alzheimer's disease and their caregivers; and demonstrated effectiveness of an approach that blended Alzheimer's disease, aging, and developmental disabilities service and support systems, and increased collaboration and cross-agency responses to the home and community-based service needs of this population.

The SUNY evaluation noted that services and training positively influenced caregivers who reported less perceived difficulty in caregiving with corresponding improvement in dementia symptoms, reduced time spent caregiving, and less burnout. The evaluation noted that environmental modifications made to day programs improved staff effectiveness and client engagement. Finally, the evaluation stated that trainings made a difference in the quality, confidence, morale, and competence of direct care workers.

The grant approach utilized a number of strategies:

- *Creating the capacity for developmental disabilities providers and family members to recognize the symptoms of dementia, secure a diagnosis of dementia, assess levels of need for dementia-appropriate services and supports and environmental modifications, and create dementia-specific care plans.* Local chapters of the Alzheimer's Association served in a consultant capacity to the developmental disabilities provider network that had not been aware of the symptoms of the disease and the resources available to help their clients.
- *Creating a network of providers offering dementia-appropriate direct services (e.g., staff time to help get ready for attending a day program) and supports (e.g., support groups).* Local chapters of the Alzheimer's Association, using Area Agency on Aging lists of aging providers, brokered service agreements with many of the same providers to offer dementia-appropriate services and supports. Over the 3-year period, 177 individuals received grant services at a cost of approximately \$5,000 per individual per year including home health care, transportation, respite, personal care, adult day care, companion services, short-term care in health facilities and other respite settings, and environmental modifications.
- *Modifying the physical space at day programs and community residences to provide a more appropriate space, augmenting the value and utility of the more traditional direct services administered through the grant.* The provision of environmental assessments and modifications was integral to ensuring the person with developmental disabilities and Alzheimer's disease remained at day programs and community residences (e.g., group homes).

- *Providing dementia-specific training and education to more than 1,000 individuals including direct care workers, family members, and social workers.* Grant stakeholders believed that the increased knowledge base led to more referrals by developmental disabilities providers for dementia-appropriate long-term care services. This increase was possible because staff were better able to identify early signs of Alzheimer's disease in the developmental disabilities population and were more skilled at working with this population.
- *Leveraging additional funding for grant partners from other state agencies and foundations to continue providing dementia services to the aging developmental disabilities population.* Several grant stakeholders successfully applied for funding from foundations and the state to support this population with services, supports, and environmental modifications and to retain dementia-specialist staff positions.
- *Increasing the flexibility and capacity of the Office of Mental Retardation and Developmental Disabilities care planning process for Medicaid services to the developmental disabilities population at day programs.* Providers utilized their increased knowledge of working with the population of persons with developmental disabilities and Alzheimer's disease to push for the approval of care plans that incorporate activities that maintain skills and ensure quality of life, rather than aim to increase skills for individuals with developmental disabilities and Alzheimer's disease.

### **Point-of-Entry Grant**

The Point-of-Entry grant is implementing a model to incorporate persons with Alzheimer's disease into the population being served by county long-term care point-of-entry systems, especially those in rural and ethnically diverse communities. Through the grant, two New York counties are integrating dementia services, education, and training to the existing long-term care point-of-entry systems.

The local Alzheimer's Association chapters are providing consultation on care planning for persons with Alzheimer's disease to Area Agency on Aging case managers; providing education and training to family caregivers, direct care staff, and other professionals (e.g., medical providers); and arranging for a full range of dementia-appropriate services for the clients in the point-of-entry system. Both entities are working with the state-funded Alzheimer's Disease Assistance Centers to secure a formal diagnosis of dementia, and to facilitate patient management and care.

The grant approach is utilizing a number of strategies:

- *Providing Alzheimer's disease services through the single-point-of-entry system creating an environment where individuals no longer have to seek services from multiple service systems.* In the first year of the grant, the Area Agencies on Aging staff in the two pilot counties consulted with staff from the SUNY Center on Excellence in Aging Services, the State Office on Aging, the Alzheimer's Association, and other relevant community providers to develop the policies and

procedures to integrate persons suspected of Alzheimer's disease into the existing point-of-entry system.

- *Enabling individuals with Alzheimer's disease to remain in the community longer through the administration of comprehensive needs assessments, the development of dementia-specific service plans, and provision of caregiver supports.* The Area Agencies on Aging are collaborating with local Alzheimer's Association chapters and Alzheimer's Disease Assistance Centers to ensure that the assessment and care planning process reflects an understanding of the unique needs and challenges of the population of persons with Alzheimer's disease.
- *Providing dementia-appropriate services and coordinating services between the providers and clients.* Both pilot counties began serving persons with Alzheimer's disease in the spring of 2006. The point-of-entry systems received a combined 80 referrals and deemed 27 individuals eligible to receive services including social adult day care, medical adult day care, transportation, personal care assistance, home health aides, housekeeping services, companion services, respite services, case management, bill payer program, and environmental modifications and representative payee assistance.
- *Meeting the needs of persons with Alzheimer's disease and their family caregivers in rural and small ethnically diverse cities by hiring a dementia-specific case manager to manage and deliver all diagnostic and direct care services.* Outreach to rural communities is ongoing; staff at the Alzheimer's Association and POE are meeting to brainstorm and strategize about how to reach out to the rural regions. Outreach to the ethnically diverse communities is a second year goal of the grant and representatives from several of these communities (e.g., refugee resettlement communities for immigrants from Belarus, Bosnia, and Vietnam) are members of the local advisory committee in Oneida.
- *Developing a directory for targeted geographic areas listing available resources to support persons with Alzheimer's disease to assist consumers and professionals in locating available service providers.* Having a current listing of resources will expedite the process of obtaining needed services and decrease the unnecessary stress of caregivers in having to seek assistance from multiple service systems.
- *Establishing a competent workforce for those caring for persons with Alzheimer's disease and other dementias by connecting families, long-term care service providers, case managers, clergy, and medical providers with dementia-specific training, providing informational and educational materials, and serving as a portal to access community resources.* The Alzheimer's Association and the Center for Excellence in Aging Services are offering train-the-trainer modules in an effort to support the ongoing education of a dementia-capable workforce once the grant ends.
- *Moving toward intensive dementia case management facilitated by the integration of point-of-entry staff with Alzheimer's disease expertise and knowledge of related services into the long-term care point-of-entry case management team, resulting in a*

*more comprehensive care plan.* The Area Agency on Aging staff have reported that case management of dementia clients has become significantly more comprehensive with the support of the local Alzheimer's Association chapters and an increasingly knowledgeable case manager staff.

- *Working to retain the position of dementia specialists on case management teams to ensure the sustainability of a formal mechanism for addressing dementia needs in long-term care planning.* One Area Agency on Aging has already made the commitment to keep a dementia specialist on the intensive case management team.

With funding from the U.S. Administration on Aging, the New York State Office for Aging and its partners created and implemented replicable methods for (1) delivering dementia services for the developmentally disabled population which allows this population to age in place; and (2) creating a model for incorporating dementia services into dementia-capable single point of entry (POE). The completed Coordinated Care grant and the ongoing Point-of-Entry grant have shown success in developing and delivering resources and services to meet the needs of individuals with Alzheimer's disease, their caregivers, and staff working in different settings.

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