

**Danita J. Vetter, M.A./Vice President of Programs and Education  
Delaware Valley Chapter Alzheimer's Association  
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Good morning. My name is Danita Vetter and I am the Vice President of Programs and Education for the Delaware Valley Chapter of the Alzheimer's Association. It is my distinct pleasure to have authored the AoA narrative of *Pennsylvania Memory Loss Screening Program*. I am pleased to be able to explain this innovative service program and the profound impact that it has had on ethnic families and those under the age of 60 years with memory loss concerns who reside in this great state.

*The Alzheimer's Disease Demonstration Grant to States and Programs (ADDGS)* was established under Section 398 of the Public Health Service Act (P.L.78-410) as amended by public law 101-157 and by public law 105-379, the Health Professions Education Partnerships Act of 1998. The Program has been administered through the Administration on Aging, within the U.S. Department of Health and Human Services.

The mission of this federal program is to expand the availability of diagnostic and support services for people with Alzheimer's disease, and their caregivers, and to improve the responsiveness from the community based care system to persons with dementia. The program focuses on hard-to-reach and underserved people with A.D. or a related memory disorder.

In June of 2002, the Pennsylvania Department of Aging was awarded this 1.05 million dollar federal grant. The Alzheimer's Association, the sub-contractor for the grant had written and developed the proposal and was charged with implementing the program and meeting the goals of *The Pennsylvania Memory Loss Screening Project*.

The state's two Alzheimer's Association chapters Delaware Valley Chapter of the Alzheimer's Association (serving 8 counties in Southeastern Pa.) and the Greater Pennsylvania Chapter, (serving the remainder of the state) shared this responsibility.

*The Pennsylvania Memory Loss Screening Project* is an innovative program designed to:

- Educate people concerned about memory loss issues, and their family caregivers, about dementia-related disease processes
- Through the memory screening process, assist those with probable dementia issues to seek comprehensive diagnosis and timely, quality medical services
- Enable families, with dementia needs, to participate in the *free* services available through the Alzheimer's Association chapters (Contact Center/Helpline, Support Groups, Family Caregiver Training, Safe Return for Wanderers Program, Care Consultation)

- Provide care management to families who are dealing with dementia to help them start a relationship with Area Agencies on Aging, community based service providers other social support systems
- Provide financial assistance, through the AoA grant, to those eligible to receive the federal respite dollars.

**Half of ALL the money awarded to the chapters through the grant is legislated to be spent on respite services for families, in the form of *adult day services, overnight respite services and in-home health services.***

Grant requires: A graduated match of federal funds: Year I – 25% (\$116,351)  
 Year II – 35% (\$188,462)  
 Year III – 45% (\$286,36)

50% of money in direct service dollars – Year I - \$232,703  
 Year II - \$ 269,231  
 Year III - \$286,364

These respite care dollars are a “lifeline” to families who for reasons related to lack of knowledge about memory loss diseases, as well as, cultural, language and geographical barriers have not been a part of *any* care system that is designed be of assistance to families with dementia-related needs. (Read attached letter from Chinese family.) *The Pennsylvania Memory Loss Screening Program* brings underserved families to dementia-related services in comfortable settings within their own neighborhoods. The program addresses medical concerns early in the dementia process when the pharmacological interventions available today work best to prolong the quality of life and delay the onset of severe symptoms. This grant project educates families about social service systems that have been developed to serve them throughout the course of the disease. It introduces families to their Area Agency on Aging (AAA) which provides access to financial programs for community based care services, as well as access to long term care services, if necessary later in the disease process.

*The Pennsylvania Memory Loss Screening Program* is beneficial to those with dementia, but is also supportive to the family caregivers, who are often a forgotten victim of the disease process. Caregivers face enormous stresses associated with progressive care responsibilities. Uneducated and unsupported family caregivers, often elderly themselves, do succumb to illnesses and may die before their loved one with dementia, because of stress factors.

In Southeastern Pennsylvania, a populous metropolitan and suburban area, the Delaware Valley Chapter Alzheimer’s Association contracted to serve three ethnic populations: the **African American community**; the **Latino community** and several **Asian communities**

(Chinese, Korean, Filipino, Vietnamese and Cambodian). These groups of citizens have historically been underserved and in the case of the African American and Latino groups, recent studies have indicated that the incidence of Alzheimer's disease is proportionally far greater within these ethnicities as compared to their Caucasian counterparts.

The Greater Pennsylvania Chapter contracted to serve the rural populations in six designated service areas.

Both chapters are able to serve families, through the AoA grant, with dementia processes when the person with dementia is under the age of 60 years, regardless of race or geography. For the purposes of this grant, these families are defined as underserved since they are largely ineligible for AAA services because of their young age at the onset of chronic disability due to a dementia process.

**Year I** of the AoA grant (July 1, 2002 – June 30, 2002) was designated as a time frame to build community capacity to provide ethnic and rural memory screening events in underserved communities. Since both Alzheimer's Association chapters are quite small as compared to the size of their mission and ever growing constituencies, the success of the memory screening project really lie in each chapter's ability to attract, train and utilize a core of effective volunteers to bring memory screenings into geographically and ethnically diverse communities. Challenges faced by chapter staff and volunteers included: language barriers, cultural barriers, mistrust of mainstream agencies, fear of dementia process, geographical distance and a paucity of community based service providers in rural areas and for ethnic populations.

Creating community partnerships and building "bridges" between the Association, service providers and community leaders were key to the goal of Year I success. Partnerships included: Area Agency on Aging(s); senior centers; houses of worship; civic organizations; ethnic family service centers, Visiting Nurses Association, medical practices/professions in ethnic and rural areas; parish nurse programs; adult day service centers; in-home service providers; congregational care settings.

These community connections, once forged through the work process, will be strengthened and preserved long after the parameters of the AoA grant timeline have expired. The social service and medical system partnerships forged in the course of this project will be a lasting legacy to the communities that were involved in *The Pennsylvania Memory Loss Screening Project*. In Year I, more than 100 community partnerships were developed, 155 volunteers trained and all of this had to be done while the screening events, slated for Year II, were in the process of being planned and scheduled.

#### **Year II – (July 1, 2003 – present)**

Memory screenings for ethnic and rural communities commenced.

A *Memory Screening* event consists of several elements. In addition to a brief, group educational program about dementia and the importance of early and comprehensive diagnosis, each screening also entails using a healthfair-style program model as a way of disseminating chapter literature, AAA materials and written materials from other senior service providers. Community attendees, with concerns about memory loss problems, who wish to be screened, may register to meet in a private, one-on-one session with a linguistically and culturally matched screening volunteer. A tool called *The Brief Cognitive Screen* (developed by the University of Pennsylvania Memory Disorders Clinic) is administered to the person with memory loss concerns, and scored in a quiet setting at the event. Those scoring poorly on the screen are counseled regarding where and how to obtain a comprehensive dementia diagnosis. They are asked to give the chapter permission to begin providing proactive care consultation around dementia issues. If the screened party agrees to chapter intervention, the chapter begins to help the family to obtain quality medical and social service care. As the case develops, the chapter assesses the family's respite needs, helps them to begin a relationship with the AAA, and enables qualifies families to begin using AoA dollars for respite care.

Year II - Pennsylvania Memory Loss Screening Program Statistics: (also see attached grids)

Total # of ethnic screenings events 31 – serving - 624

# of African American Screening events 22, serving 451

# of Latino Screening events - 4, serving 74 ( hired new Coordinator 9/04)

# of Asian Screening events 5, serving 99

# screened with memory loss issues needing medical attention: 94

Percentage of screened citizens needing follow-up services 15.05%

# of volunteers recruited and trained to provide screening and I&R - 155

# of rural screening events 6, serving 40

# number of state-wide community service respite providers - 45

# of people state-wide receiving AoA respite funding -66

Waiting list – 36 families have been identified as eligible for federal dollars for respite services, but are not being served yet due to the financial constraints imposed due to underutilization of federal match dollars. With each additional screening this list of potential respite users grow.

At this time, the Delaware Valley Chapter has been forced to begin to curtail respite service funding for families who have received respite dollars since July 2003. This is happening in an effort to serve additional families within the constrained AoA budget. This is especially difficult for persons/family caregivers under the age of 60 who are

shouldering the cost of care without much assistance from AAA sources of funding due to the young age to the person with dementia.

*The Greater Pennsylvania Chapter is no longer providing any memory screenings or related AoA respite service dollars to the rural population of the state.* The chapter was unable to sustain the cost of the program without the free flow of monthly payments to support the chapters as they go about this important work. As of April 30, 2004, the Greater Pennsylvania Chapter is no longer a part of *The Pennsylvania Memory Loss Screening Program*. This result is so deflating especially since there are so many positive outcomes associated with this AoA project.

#### Positive AoA Grant Outcomes

- Brings springboard to dementia service constellation directly into underserved neighborhoods
- Easy access to services for diverse and rural communities
- Provides culturally and linguistically matched programming to community
- Brings ethnically diverse clients to AAA services
- Fosters excellent AAA/chapter relationships
- Mandatory translation of written dementia literature for family/community use
- Brings linguistically appropriate education programs about dementia to underserved populations
- Creates pools of dementia savvy volunteers in neighborhoods
- Helps houses of worship to focus part of their mission on dementia care for aging congregants
- Brings additional clients to free Alzheimer's Association services
- Gives family caregivers "permission" to seek outside help for 24 hr responsibilities
- Enables families to be introduced to and "test out" the benefits of respite services
- Creates a way to easily discuss and plan to deal with caregiver stress/depression
- Create a pool of funding for community based service providers
  
- Creates working relationships and enhanced communication between community service providers, the Alzheimer's Association and families
- Encourages service providers to hire and retain ethnically diverse workers
- Creates better working relationships between medical and social service providers
- Focuses media attention on families dealing with the challenges of dementia
- Raises public awareness of problems associated with dementia processes

I am proud to say that over the course of nearly two years of the AoA grant, the chapters met *every one* of the goals and objectives set forth in their original AoA grant proposal. In fact the program has been so successful, in Southeastern Pennsylvania, that the

Delaware Valley Chapter projects that it will double the number of screenings delivered and the number of people served through the screening process and through Alzheimer's Association services. From a programmatic point of view, the concept and actualization of the services set forth in the grant has been stellar.

The model of this program has been so successful that the chapter plans to share the structure and results of our findings with other chapters around the nation who wish to reach underserved populations. The *Pennsylvania Memory Loss Screening Program* is replicable and has proven to be an effective means to bring people to dementia-related services, assist them in getting quality medical, engage them in education and support services, and assist them in exploring respite services.

From a fiscal point of view, the outcomes have been less than positive. Ms. Wendy Campbell, Delaware Valley Chapter President, will elaborate on the funding woes that have constrained this exemplary service program. I am hoping that the state of Pennsylvania will reinstate match funding for *The Pennsylvania Memory Loss Screening Program*, as every dollar spent at the state level brings federal money to families who are struggling with dementia.

People who seek the proper medical care early in the process, get educated and supported and engage in respite services, proactively, are more likely to remain in the community longer saving or delaying the cost of long term care placements. Caregivers who are supported reduce the likelihood of morbidity and mortality associated with the stress of full time caregiving. This program is a model that truly works...for families...for community medical and social service infrastructure, for our Department of Aging as we strengthen the ties to local AAA services and programs...and for our government....since community care costs are much lower than the cost of institutionalization. *Please support the match funds for the Pennsylvania memory Loss Screening Program.*