

TESTIMONY

Pennsylvania House Aging and Older Adult Committee

Alzheimer's Disease:

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PRESENTED BY:

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Good morning, Representative Mundy and members of the House Aging and Older Adult Services Committee:

As Executive Director of the PA Association of Area Agencies on Aging, I would like to share with you the Area Agencies on Aging's (AAAs) perspective on the impact Alzheimer's disease has on the population we serve as well as some of the services and resources we utilize to help support consumers and their caregivers. Every hour of every day, Pennsylvania's 52 AAAs find themselves working with consumers and families impacted by Alzheimer's disease, one of the senior population's most dreaded diseases. Alzheimer's is a disorder that lies in wait for seniors. If you live to be 85, there is a 50% chance that you will have some form of Alzheimer's. It is an equal opportunity disease, giving

little regard to race, ethnicity, education, or income. With the advent of the “baby boomers”, the number of individuals projected to suffer from Alzheimer’s disease and related dementias is expected to increase dramatically. This makes Alzheimer’s disease is an emerging public health problem that poses a high societal burden.

As we look at the population supported with services through the Area Agencies on Aging, about 27% of all services, and 40% of care managed services, are provided to individuals 85+. So you can see Alzheimer’s is of significant concern for us. The entire spectrum of services offered through AAAs is designed to enable older adults to live as independent and productive lives as possible including even those who are most significantly impacted by Alzheimer’s and other related dementia’s.

Our agencies see individuals and families at every stage of the disease and at every level of family stress. Because we are seen as a focal point for services and supports for the senior population, we receive thousands of calls from consumers and families looking for information and services. It may be fear of what they may be seeing happen in a loved one's life, or sense of desperation of not knowing how they are going to get through the next day, AAAs help consumers and families get connected with available resources in each community. Often we look to the Alzheimer's Association. Whether it is for information, or support and assistance to consumers and to caregivers, the Alzheimer's Association is our partner in helping seniors and their family members. AAAs are experts in knowing the resources that exist in each community, not just those provided through governmental programs.

Whether that is a PACE/LIFE center, a parish nurse program, an elder law attorney or an exercise program offered by the local YMCA or YWCA, AAAs look to help get consumers connected with the services and supports they need.

Another way AAAs communicate to potential consumers and their families is through community outreach such as newsletters, writing columns in local newspapers, speaking at clubs, organization functions, etc. Each of them also targets special efforts to underserved populations including working in communities and neighborhoods where low literacy and limited-English proficiency impair access to services and community resources. Additionally, the AAA network of 650 senior centers across Pennsylvania serve as community supports centers for more than 10% - 20% of the senior population. Because participation is often regular, senior

centers are often one of the first places, outside families, to observe signs and symptoms of Alzheimer's disease and encourage appropriate screening and treatment. Many of the individuals who attend programs may be in various stages of the disease. Senior centers design programming with that understanding. They also are community centers that often provide support programs for spouses and other caregivers.

As I indicated AAA programs focus on helping people live independently. Pennsylvania was a National Leader in establishing the Family Caregiver Program. It acknowledged that families are the major source of support and that without them we all suffer. The State Family Caregiver Program, which initially was funded through the General Fund and now supported through the Lottery, acknowledged that families are often paying for services and supplies with their own funds. The

Family Caregivers Support Program provides assistance to caregivers through education, family-centered benefits counseling, care management, limited reimbursement for supplies as well as services related to care giving including home modifications or adaptive equipment. Although most people with the disease also have at least one other chronic illness, many are physically and functionally well enough to be at significant risk for wandering and other unsafe behaviors. Examples of specific service needs include supervision, caregiver respite and safety devices such as door alarms and home sensors. The Family Caregiver Program enables our agencies to provide a range of services and supports to care givers including starting support groups for families.

In the late 1990's, the Federal Government established a program which was similar to Pennsylvania Family Care

Giver Program in many ways. It helps us meet the needs of families who are providing support, but who do not meet the very strict definition of the State's Family Caregiver Program. Let me thank the members of the Committee for their support to families in helping update Pennsylvania Family Care Giver Program. Two hundred dollars, which is the monthly limit for the State Program, does not go very far in today's economy. We are hopeful that the Senate will follow your lead and update the State Family Care Giver Program.

Everyone has their own story of how critical it is to reach out and support families. I have one I would like to share with you. When I was Director of the York County AAA, one of the community volunteers I worked with was a former teacher, a woman who had taught on both a high school and college level. She was active in her church, in a number of civic organizations as well as being very

involved in our local AAA. She had a son who lived out of state, but also had sisters and brothers who lived close by that she interacted with on a weekly if not daily basis. We worked together often and one day we were talking about her husband, who I had never met, she mentioned his progressive physical and mental disease. I happened to inquire about the kind of support she had to help and she mentioned that she had been coping ok, but that recently when she left she had been tying him down in bed so that he would be safe. It still pains me to think of that. She felt she was doing the "right thing". She didn't want to bother anyone. She didn't want to be a burden. She felt that restraint was best for him. She felt she was doing ok. As you might expect, I needed to make a Protective Services referral. We supported her and helped her ask for and accept the help that enabled her to safely provide care to her husband at home until his death several years later.

My friend and her husband were in need, and finally accepted formal services. As we work with families who come to that point, each AAA completes a comprehensive assessment. It helps identify their unique needs. Needs range from making the home environment safe, accessing public benefits in order to have the financial resources to meeting daily life necessities, to providing support services to help the individual maximize their independence. Part of the assessment includes a caregiver stress assessment to identify the kind of interventions and supports that a caregiver may be facing. It is one of the most important parts of the assessment.

Please bear in mind that not everyone we encounter understands Alzheimer's disease. All too often we encounter individuals who believe that some of the

symptoms and behaviors that are beginning to see are malicious and done on purpose. Frustration is common, both on the part of the older adult as well as the caregiver. When you realize that 70% of those with Alzheimer's are live at home, the impact of the illness extends to millions of family members, friends and caregivers. The importance of supporting families cannot be underestimated.

People with Alzheimer's disease rely heavily on caregivers to help them with their daily activities and to maintain their quality of life and safety. As more and more caregivers choose to care for loved ones at home, the need for services and support for families will continue to increase. Area Agencies on Aging can tap into a variety of publicly funded home ad community based services., including the Lottery funded OPTIONS

Program, the State and Federal Family Care Giver Program as well as or the Aging Waiver.

Community programs such as Adult Day Centers and Pace/Life Centers enable some of our most frail and mentally impaired seniors to live in the community. Programming is designed to provide support, supervision, socialization. Adult day like programs enable many families to continue to remain employed supporting both themselves and their families. For others, it offers the respite they need to take care of themselves so that they can continue to provide care and support. For many seniors who attend the programs, it gives their lives purpose; it is often reminiscent of either work or school providing a structure that is routine, reassuring and a comfort.

Not everyone can be maintained at home. We help families make difficult choices, identify options, risks and other community resources that may meet their needs. For some, options such as personal care homes, assisted living units, or nursing homes are the “right” choice for them. Once a placement has occurred, AAAs remain involved, as the Ombudsman Program continues to work with consumers and their families, helping each individual maintain their rights within facilities.

In closing, I would like to affirm that Alzheimer’s disease is the most common cause of dementia among older adults. The Alzheimer’s Association reports that the primary risk factor for Alzheimer’s disease is advancing age. Individuals 85 years of age and older currently comprise nearly 50% of the persons with the disease or approximately 2.7 million people nationally. As our

population ages, we must deal with Alzheimer's as a social and public health issue.

AAAs firmly believe that special attention must be paid to address this national epidemic. Since no cure appears on the horizon, we must begin to bring greater attention to research, identification, and provide adequate resources to support consumers and their families who live with the terrible realities of this disease.

Thank you for holding this hearing today and allowing the AAA network the opportunity to express our concerns.