



**Testimony of Secretary Teresa Osborne
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United States Senate Special Committee on Aging

*Changing the Trajectory of Alzheimer's: Reducing Risk, Detecting
Early Symptoms, and Improving Data*

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Thank you, Senator Collins and Senator Casey for the opportunity to testify at this important hearing that is focused on changing the trajectory of Alzheimer's by reducing risk, detecting early symptoms, and improving data. It is a true privilege to be before you and this committee, as advocates from across the country gather here in Washington, D.C. to advance policies intended to improve the lives of all individuals affected by Alzheimer's disease.

As Secretary of Aging for the Commonwealth of Pennsylvania, I have the honor of serving at the pleasure of Governor Tom Wolf, who has made it a priority that we uphold the provisions of the Older Americans Act, which calls us to serve as visible and effective advocates for older Americans. In my role, I have the awesome opportunity to meet with and listen to individuals and families in communities throughout Pennsylvania, and I have seen firsthand how the Older Americans Act and the aging services network supports the values that we all share: helping older adults and persons with disabilities live and age well in the setting of their choice for as long as possible; developing and implementing a person-centered approach to care; promoting inclusion and empowering independence and self-determination; protecting the most vulnerable among us from all types of abuse, neglect, and exploitation; and providing basic respite care and other supports for caregivers so that they are able to take care of loved ones in their homes and communities, which is what each of us desires and deserves.

Of the nearly 13 million citizens who call Pennsylvania 'home', 3 million are age 60 and over. By the year 2020, 1 in 4 Pennsylvanians will be 60 years of age and over. Within our 67 counties of the commonwealth there are 52 local area agencies on aging. Under the Older Americans Act, these area agencies on aging serve as "on-the-ground" organizations charged with helping vulnerable older adults live with independence and dignity in their homes and communities. Each area agency on aging plays a key role in helping us plan, develop, coordinate, and deliver a wide range of long-term services and supports to older adults in communities throughout Pennsylvania.

To this end, and for our purposes today, I will focus my attention specifically on the estimated 280,000 Pennsylvanians who are living with Alzheimer's disease, and will clarify that the number is closer to 400,000 when we add in those living with related disorders. Furthermore, nearly 675,000 Pennsylvania caregivers are providing a total value of \$9 billion dollars in unpaid care to loved ones with dementia. Alzheimer's disease is the 6th leading cause of death in the

country, as well as in the commonwealth of Pennsylvania. All told, one in twelve Pennsylvania families are affected by Alzheimer's disease and other related disorders.

For far too many years, Alzheimer's disease has been treated as an "aging" issue. Yet, it's impossible for us to continue to ignore the public health consequences of a disease that someone in the United States develops every 66 seconds. Alzheimer's is the nation's most expensive disease, costing \$277 billion in 2018, including \$186 billion in costs to Medicare and Medicaid. It is the only leading cause of death in the United States without a way to prevent, cure, or even slow its progression. There are no survivors. Like many, if not most, who gather in Washington, D.C. today, I am passionate about working to end this disease, as I have witnessed first-hand the human consequences of this disease on countless Pennsylvanians and their families, including members of my own family.

In Pennsylvania, we believe the Alzheimer's trajectory can be influenced and changed by increasing our country's commitment to Alzheimer's research, building an Alzheimer's public health infrastructure, and leveraging Older American's Act services to bend the cost curve on the growing costs associated with caring for individuals with Alzheimer's disease.

With much appreciation, Congress continues to fund Alzheimer's research at the United States National Institutes of Health. This Congressional commitment to fight against Alzheimer's is further demonstrated through the National Institute on Aging (NIA), a division of the National Institutes of Health, which funds Alzheimer's Disease Centers at major medical institutions throughout the United States. Every day, researchers at these Centers focus their efforts on translating research advances into improved diagnosis care for individuals with Alzheimer's disease. Moreover, these researchers are incredibly motivated to identify any and all activities that can help to diagnosis, treat, prevent and cure Alzheimer's. For those diagnosed and their families, thirty-two Alzheimer's Disease Centers in twenty-one states, offer help and hope by also providing information about the disease, services, and resources; offering opportunities for volunteers to participate in clinical trials, studies, and patient registries; and connecting those diagnosed and their families with support groups and other special programs.

Potentially ground-breaking research is being conducted at two NIA-funded Alzheimer's Disease Research Centers in Pennsylvania, including the Penn Memory Center, which is located in Philadelphia at the University of Pennsylvania, and the University of Pittsburgh

Alzheimer's Disease Research Center in Allegheny County. These remarkable Pennsylvania-based Alzheimer's Disease Research Centers collaborate with other academic research groups, along with pharmaceutical, biotechnology, and diagnostic companies. They play a substantial role in advancing knowledge and developing new treatments and diagnostic technologies; and help to well position Pennsylvania to build upon its strong base in research and technology, not only in the pursuit of improved care and treatment for people with Alzheimer's, but also as an engine for economic development.

Pennsylvania's current infrastructure is thus in perfect alignment with the country's need to further invest in a nationwide Alzheimer's public health response that will promote better treatment and care for those living with Alzheimer's. The BOLD (Building Our Largest Dementia) Infrastructure for Alzheimer's Act is proposed to establish Alzheimer's Centers of Excellence across the country by funding state, local and tribal public health departments to increase early detection and diagnosis, reduce risk, prevent avoidable hospitalizations, reduce health disparities, support the needs of caregivers, and support care planning for people living with the disease. These important public health actions are already embedded in both Pennsylvania's State Plan on Aging, which is required under the Older Americans Act, and our State Plan on Alzheimer's Disease and Related Disorders, which is dedicated to helping persons with Alzheimer's to age in place in their homes, and to delay costly institutionalization care for as long as possible. Due to the strong foundation already laid, we believe that Pennsylvania is well-prepared and perfectly positioned to boldly take action by hosting an Alzheimer's Center of Excellence.

Further evidence of this preparation is the fact that while the first national plan to fight Alzheimer's disease was presented in May 2012 at the Alzheimer's Research Summit, Pennsylvania's call to action occurred in February 2013 when then Governor Corbett signed an Executive Order establishing the Pennsylvania Alzheimer's Disease State Planning Committee. This committee was charged with developing a state plan to address the growing Alzheimer's disease epidemic in the commonwealth. In crafting a plan for Pennsylvania, the committee heard from representatives from the diverse communities that comprise our state. Pennsylvania is the nation's sixth most populous state--our residents live in urban, suburban, rural, and frontier communities. Pennsylvania is the second most rural state in the nation. According to the U.S. Census Bureau, nearly 27% of the state's residents lived in 48 rural counties in 2010. By 2030, this number is projected to increase by 3%. Moreover, the committee learned that in order

to address the enormous breadth of what is included in a statewide endeavor to help fellow Pennsylvanians living with and caring for someone with Alzheimer's disease, partnerships are necessary for our communities to become places to live and age well. Ultimately, the committee developed seven overall recommendations that were designed to mobilize the commonwealth's response to the current and anticipated increase in the prevalence of Alzheimer's disease and related disorders in Pennsylvania.

Unveiled in February 2014 as the Pennsylvania State Plan on Alzheimer's Disease and Related Disorders (ADRD), its seven overall recommendations are:

1. Improve awareness, knowledge, and sense of urgency about medical, social, and financial implications of ADRD.
2. Due to the magnitude of the ADRD epidemic, identify, and where possible, expand financial resources to implement this plan through federal, state, foundation, private, and other innovative funding mechanisms and partnerships.
3. Promote brain health and cognitive fitness across the life cycle from birth onward.
4. Provide a comprehensive continuum of ethical care and support that responds to social and cultural diversity, with services and supports ranging from early detection and diagnosis to end of life care.
5. Enhance support for family and non-professional caregivers and those living with ADRD.
6. Build and retain a competent, knowledgeable, ethical, and caring workforce.
7. Promote and support novel and ongoing research to find better and effective cures, treatments, and preventative strategies for ADRD.

Under the Wolf Administration, we have continued to evaluate progress made, while also assessing and determining where to focus current and future efforts. Regularly, we find ourselves pivoting back to public-private partnerships serving as the best way to strengthen the ongoing need for research in pursuit of a cure. Simultaneously, we recognize that we need to put into practice what we know about prevention, while enhancing the quality of care and support for those living with Alzheimer's and their families and friends who support them in their Alzheimer's journey. In partnership with the Alzheimer's Association, Pennsylvania has been laser-focused on helping those facing memory problems and other cognitive deficits which affect daily life, to first talk with their physician. We then work with physicians to fast track their patients immediately following a diagnosis to an easy-to-use Next Step Direct Connect referral program. We recognize that once there is a dementia diagnosis, it is never too early or too late

for a referral to the Alzheimer's Association's Helpline, where family care support is available 24 hours a day, seven days a week. Via early detection, patients and their families can receive the maximum benefit from available treatments for dementia and related conditions, and with a referral to the Alzheimer's Association, they can more easily create a care plan to address immediate needs, as well as get referrals to resources for assistance with current and future planning.

Pennsylvania's investment in its State Plan on Alzheimer's Disease and Related Disorders and its partnership with the Alzheimer's Association was further strengthened last month, when Governor Wolf capped off Older Americans Month by announcing the formation of Pennsylvania's Alzheimer's State Plan Task Force. The 15-member task force was created to take the lead role in implementing and championing the goals and recommendations of Pennsylvania's State Plan for Alzheimer's Disease and Related Disorders. We recognize that the toll of this disease extends beyond those affected to their families, friends, and communities, and believe that with task force members who are passionate and engaged partners from geographically and personally diverse backgrounds, Pennsylvania's fight against Alzheimer's will have immediate, positive, and lasting impacts. Task force members will focus on working with local organizations, entities, advocates, and other stakeholders to identify and share best practices that support the goals and overall success of the plan, will lead efforts to review and revise the State Plan, will develop and facilitate the actions needed to carry out the State Plan, will pursue research and review any other issues that are relevant to Alzheimer's disease and related disorders, will assist in the planning of our Annual Alzheimer's Disease and Related Disorders Forum, and will assist in the development of an annual update to the State Plan. Two prominent Alzheimer's Association advocates, Bob Marino and Clay Jacobs, are serving on the task force, which further demonstrates our commitment to work together as unrelenting advocates for public policy at all levels of government that advances research and improves access to care and support services for persons with Alzheimer's and their caregivers.

Lastly, from our lens at the Pennsylvania Department of Aging, whenever we talk about health care and the elderly, we immediately refer to three landmark federal programs that were created fifty-three years ago: Medicare, Medicaid, and the Older Americans Act. While Medicare and Medicaid began as basic health care programs, over the years they have evolved where they now provide Americans with improved access to quality and affordable health care coverage. Notwithstanding, in today's challenging times, it's the Older Americans Act that is enabling the

aging network to play a central role in bending the cost curve on the growing costs of two very large federal entitlement programs.

Every day, in communities across the country, State Units on Aging, in partnership with their network of local area agencies on aging, through the provision of Older Americans Act services, help older Americans remain healthy, work longer, stay connected with their community, avoid hospitalizations or re-hospitalizations, and defer altogether or transition from nursing homes. In addition, the Older Americans Act also encourages its aging network to provide access to evidence-based health promotion and disease prevention programs, such as chronic disease self-management, healthy steps for older adults, 10 keys to healthy aging, and healthy steps in motion, along with immunization, vaccine and health screenings, all of which helps to reduce health care costs for older adults with chronic conditions, which are the biggest drivers of Medicare spending. Moreover, experience has shown that the home and community-based services provided under the Older Americans Act, such as personal care assistance, support for caregivers, nutritional programs, and transportation services, when targeted properly and delivered effectively, reduce other areas of concern that drive costs, such as hospital readmissions.

Older Americans Act services provides critical federal funding and the necessary infrastructure to deliver vital support programs and social services to seniors throughout the country, including those with Alzheimer's disease and related disorders, as well as their millions of unpaid family caregivers, through programs such as the National Family Caregiver Support Program, which supports low-income seniors with dementia. Since its enactment, the Older Americans Act has kept millions of older Americans healthy, independent, secure, and able to live at home for as long as possible. For the past five decades, Older Americans Act services have grown and adapted to many of our nation's changing needs. In every setting and through each advancing year, Older Americans Act services support health, foster independence, and promote dignity. The programs authorized by the Older Americans Act have never been more important to individuals, to families, and to communities throughout the country. Congress's continued support and reauthorization of the Older Americans Act reflects its commitment to the health and well-being of the aged and aging in America. It also furthers its support of the aging network and its capacity to rebalance the long-term care system by building on the non-Medicaid community-based support system embodied in the Older Americans Act. These are the steps

necessary to promote prevention, improve treatment, and ensure access to services for those living with Alzheimer's and the caregivers who journey with them.