



**Pennsylvania House Aging and Older Adult Services Committee  
Hearing on HB 2400 and SB 840  
Alzheimer's Disease and Related Disorders Office Infrastructure  
June 10, 2024**

Good morning. My name is Clay Jacobs and I am the Executive Director of the Alzheimer's Association, Greater Pennsylvania Chapter. First, I would like to acknowledge and thank Chairwoman Madden, Chairman Mentzer and Members of the House Aging and Older Adult Services Committee, for convening this hearing on the Alzheimer's Disease and Related Disorders (ADRD) Office Infrastructure - specifically House Bill 2400 and Senate Bill 840. I also would like to recognize and thank Secretary of Aging, Jason Kavulich, who also is testifying, for his leadership on the issues before us today.

Last week this committee was gracious enough to hear from leading researchers, clinicians, public health experts and families about the impacts of Alzheimer's and dementia. Today, as we discuss proposed initiatives that can make a difference for Pennsylvanians, it is my privilege to share some brief examples of the success and return on investment other states have seen as a result of similar infrastructure efforts.

While Pennsylvania has one of the largest older adult populations, world class research institutions, many quality care providers, a strong network of Area Agencies on Aging and more, it lags significantly behind peer states in its coordinated approach to dementia. As a result, our most vulnerable citizens are often left to navigate the disjointed system all on their own, doing the best they can. And this is before we even consider the significant advancements coming around risk reduction, biomarker testing, FDA-approved treatments and more, which we know will impact patient care in the community in the near term.

I say this because other states across the nation have recognized that the policies and programs needed to effectively confront the Alzheimer's public health crisis are wide-ranging and cross multiple state agencies, requiring significant interagency coordination. In contrast, Pennsylvania last updated its State Plan for Alzheimer's Disease & Related Disorders in 2014, and the majority of recommendations included within have remained largely unaddressed, or are now out of date given recent scientific advancements, despite efforts across multiple administrations. This is also the reason why most other states have created a permanent Alzheimer's council or task force to monitor the state's response to Alzheimer's through implementation of their state Alzheimer's plan, and to determine what actions need to be addressed in future plans. This is what makes the current efforts underway, including Senate Bill 840, the Governor's budget proposal to fund this work and House Bill 2400, so vital and timely.

A coordinated state Alzheimer's plan and adequate resources enable the state to respond to the Alzheimer's crisis with recommendations tailored to the most timely and critical issues and, most importantly, with direct action and accountability. As federal and state policies change regularly,

# ALZHEIMER'S ASSOCIATION®

coupled with emerging research and new programs, any plan can quickly become irrelevant and ineffective if there are no reports on implementation status, and if it is not regularly updated.

Last week you heard about what research and public health experts consider vital to addressing dementia now and in the near future. Yet currently, Pennsylvania only allocates \$250,000 towards dementia-specific disease education, outreach and programming. With more than 280,000 Pennsylvanians aged 65 and over living with Alzheimer's disease, that is less than one dollar per every Pennsylvanian diagnosed, and this is putting Pennsylvania even further behind peer states.

States that have invested in a dementia-specific health infrastructure, similar to what has been proposed for the State of Pennsylvania, have not only improved the state's response to this growing public health crisis, but those states have also leveraged their investments into increased access to federal funding and direct benefit to their citizens.

This approach is not new or unique. In fact, 28 states plus the District of Columbia have a state-funded position within state government, often referred to as a Dementia Services Coordinator. Due to scientific advancements and increased need, in October 2022, the Alzheimer's Association hosted the first annual Dementia Services Coordinator Summit in Washington D.C. This was the first gathering of Dementia Services Coordinators from states across the nation, where Dementia Coordinators were able to share ideas and learn about effective responses to Alzheimer's and dementia. In addition to practical discussions about implementation, the Administration for Community Living, which is housed within the Department of Health and Human Services, presented to attendees about federal grant opportunities to aid in that implementation, including the Alzheimer's Disease Programs Initiative (ADPI) grant, that are available to state agencies to implement policies and support the delivery of critical programs and services that support dementia caregivers within their state.

As just one example of how states are capitalizing on this federal funding, we look to the State of Wisconsin. Between 2009 and 2022, the State of Wisconsin, through their Dementia Services Coordinator working within the Department of Health Services, secured \$4,731,061 in grant funding from the Administration for Community Living. The nearly \$5 million has funded various projects like a Memory Screening Pilot program to ensure early detection and diagnosis, which became one of the tenants of the highly successful county-based dementia care specialist program in Wisconsin. Additional funding from an ACL's ADPI grant supported the adaptation of that Dementia Care Specialist (DCS) model for the Lac Courte Oreilles tribe and the Hispanic community in the southeastern part of the state.

The State of Wisconsin's Dementia Services Coordinator also secured two separate rounds of funding from the Centers for Disease Control and Prevention (CDC), specially the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act. The first award, secured in 2021, provided Wisconsin's Department of Health Services with \$300,000 per year, for three years. The second award will provide the state with nearly \$2.5 million over the five-year lifespan of the



grant, to use a public health approach to address Alzheimer's disease and related dementias by implementing the CDC's "Healthy Brain Initiative: State and Local Public Health Partnerships to Address Dementia." That plan is a step-by-step, evidence-based guide on how to improve health outcomes in issues related to cognition.

By the end of the current BOLD grant funding cycle, the State of Wisconsin will have secured more than \$8.1 million in federal funding to address Alzheimer's and related dementias, all of which began with a coordinated plan and a commitment to having an established infrastructure.

States all across the country are transitioning their state Alzheimer's plans to direct funding of services, creation of programs, and providing direct support to persons living with dementia and their caregivers. For example, Kansas and Tennessee have recently created new dementia-specific respite programs administered by their state's Area Agencies on Aging (AAAs). Missouri, over the past two years, has nearly tripled the amount of funding provided to their non-profit administrator of their dementia-specific respite program.

Other states, including Virginia, Georgia, and again, Wisconsin, are creating innovative care delivery models for persons living with dementia. The State of Virginia has created two separate appropriations to specifically fund case management for individuals living with dementia. The University of Virginia and the Martha W. Goodson Center of Riverside Health Services receives state funding for dementia case management to ensure a comprehensive care coordination and management plan is created and focused on the individual's underlying dementia diagnosis. The end result is improved quality of life for people living with dementia, a reduction in strain on their unpaid caregivers, and enabling people living with dementia to remain in their homes, as long as it is the most appropriate care setting.

In Georgia, the state has partnered with Emory University to create a statewide program, known as Georgia Memory Net, to expand access to early and accurate diagnosis of Alzheimer's disease and other dementias, and to help support those living with dementia, including caregivers. Additionally, Georgia Memory Net trains physicians to properly screen for the disease, and collect useful data which allows the state to better support those living with dementia. Created in 2018, the Georgia Memory Net program currently has five Memory Assessment Clinics (MACs) in operation across the state. Today, the program is more timely and necessary than ever before, as the current FDA-approved treatments are focused on the earliest stages of Alzheimer's, making early detection and diagnosis even more imperative.

Again, the State of Wisconsin has focused significant funding and effort on a collaboration with their county governments, with the 2013 creation of the Dementia Care Specialist (DCS) Program. The State of Wisconsin provides \$9.28 million each biennium through grants to Wisconsin counties and Tribal Nations to fund 58 DCS positions statewide. Every county in Wisconsin has funding for, and is served by a minimum .5 FTE position, with many counties having a full-time DCS position. Additionally, each of Wisconsin's 11 Tribal Nations is served by their own, dedicated DCS position. The DCS Program supports people with dementia and their

# ALZHEIMER'S ASSOCIATION®

caregivers in order to ensure the highest quality of life possible while living at home. This program provides positions dedicated to supporting people with dementia and their families by providing dementia-specific information, care planning, cognitive screenings, county employee training, and consumer-directed personal care. The investment Wisconsin has made on supports and services, particularly through the DCS program, to assist individuals residing in their homes longer, ultimately saves state Medicaid dollars as the need for more expensive, institutionalized care is delayed, or even eliminated.

The common thread in all of the aforementioned examples is each program, or state-based effort began with the allocation of specific resources and the development of an infrastructure designed to holistically approach dementia. This was coupled with a commitment—at all levels of government—to enact real, meaningful change for residents in each state. This level of understanding and commitment aligned these states with public health best practices, and opened up avenues for additional public and private funding necessary to implement said programs.

We are on the precipice of great, positive change for our residents impacted by Alzheimer's and all other dementias. At this moment, we have the opportunity to improve care, and support providers, families and those living with the disease, while also increasing revenue into the Commonwealth—this is what needs to be the focus as you consider this legislation.

As the leading advocacy organization for families impacted by all dementias in Pennsylvania, we hear, all too often, the familiar refrain you heard last week: "We did the best we could with what we had." Each time a family shares this sentiment, or discusses the added layers of stress and time needed to navigate and coordinate care on their own, we know that they have been failed by the current system. At this moment, under this administration and this current Pennsylvania General Assembly, we have the ability to change that experience for millions of residents, and to forge a better path as we enter a new era of treatment and quality care in our community.

Thank you Chairwomen Madden, Chairman Mentzer and Members of the House Aging and Older Adult Services Committee for the time and for the invitation to be here with you today.

Respectfully Submitted,



# ALZHEIMER'S ASSOCIATION®

Clay Jacobs, Executive Director  
Alzheimer's Association Greater Pennsylvania Chapter  
[cjacobs@alz.org](mailto:cjacobs@alz.org)