Testimony

In Support Of

LD 2125, An Act to Establish the Alzheimer's Disease and Other Dementias Advisory Council Within the Department of Health and Human Services and to Require a State Plan to Address Alzheimer's Disease and Other Dementias

Jill Carney
Director of Public Policy
Alzheimer’s Association, Maine Chapter

Before the Joint Standing Committee on Health and Human Services

January 24, 2024

Senator Baldacci, Representative Meyer, and members of the Joint Standing Committee on Health and Human Services:

My name is Jill Carney, Director of Maine Public Policy for the Maine Chapter of the Alzheimer’s Association. On behalf of the Maine Chapter, I am pleased to register our strong support of LD 2125, which would ensure Maine appropriately prioritizes the fight against Alzheimer’s disease by establishing a Dementia Advisory Council and requiring a State Plan to Address Alzheimer’s Disease and Other Dementias.

Alzheimer’s is a public health crisis in Maine and across the nation. In Maine, there are 29,000 people living with dementia, and that number is projected to reach 35,000 by 2025. As the population ages and people live longer, the prevalence of Alzheimer’s will continue to grow in the decades beyond. Alzheimer’s is also one of the costliest diseases to society; currently, $345 billion is spent on care for people living with dementia nationwide, increasing to nearly $1 trillion by 2050. Given these significant challenges, state action to increase public awareness, promote early detection and diagnosis, and expand access to quality care, particularly in underserved areas, is critical to better managing dementia, supporting affected families, and reining in costs.

In 2011, Maine was one of the first states nationwide to take a serious look at addressing Alzheimer’s statewide. Following leadership from Representative Margaret Craven, Maine created its first State Plan on Alzheimer’s. Momentum on the plan and its recommendations, however, waned in subsequent years without resources and infrastructure to continue prioritizing these issues.

That changed in 2019, however, when the Maine CDC was awarded funding from the U.S. CDC through the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer’s Act,
authored by U.S. Senator Susan Collins and signed into law in 2018. Maine’s BOLD Act grant enabled it to rebuild and establish Maine’s State Plan on Alzheimer’s. As part of this process, Maine CDC convened a stakeholder group consisting of a wide array of community partners and experts with experience in several categories of issues related to dementia, including public awareness, access to care, caregiver supports, workforce, legal issues, and research and data. Participants met regularly to examine research and data pertaining to dementia, identify opportunities for improving dementia care in Maine, and crafting recommendations. Last year, Maine’s State Plan on Alzheimer’s was finalized and released, and one of the key recommendations is for Maine to codify an independent Dementia Advisory Council.

Codifying this stakeholder group and establishing responsibilities for monitoring and updating the Maine State Plan on Alzheimer’s will ensure that Maine continues to engage these dedicated stakeholders and make progress toward the recommendations. Last year, Maine CDC was awarded with another BOLD Act grant to help the state implement the newly updated State Plan on Alzheimer’s and expand Maine’s public health capacity for addressing dementia, so these efforts will continue to benefit from additional federal funding over the next five years and will have minimal fiscal impact on the current state budget.

Several states have recognized on a bipartisan basis the significant value of formally establishing stakeholder groups to better address dementia. To date, 19 states have established Dementia Advisory Councils in statute, and other states in addition to Maine are considering proposals to establish Dementia Advisory Councils in 2024.

Maine is fortunate to have many professionals across several fields related to dementia care that are dedicated to making Maine a better place to live with Alzheimer’s. Establishing a Dementia Advisory Council and requiring regular updates to the State Plan would capitalize on the expertise of this group and promote continued progress and partnership on Alzheimer’s issues in the years to come. It would also strongly signal the Legislature’s commitment to the 29,000 people living with Alzheimer’s and the 51,000 unpaid family caregivers grappling with this disease every day.

Thank you for considering passage of this bill.

Jill Carney
Director of Public Policy
Alzheimer’s Association, Maine Chapter
383 U.S. Route One Suite 2C
Scarborough, ME 04074