



Maine Chapter

Testimony

Relating to

L.D. 1677, An Act to Establish the Alzheimer's Disease and Related Dementias Prevention and Support Program

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Before the Joint Standing Committee on Health and Human Services

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Senate Chair Ingwersen, House Chair 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 Alzheimer's Association, and a resident of Cumberland. The Alzheimer's Association urges the Committee to support L.D. 1677, which would codify current efforts to address Alzheimer's in Maine, including: establishing the Alzheimer's Prevention Program at the Maine CDC; establishing the Healthy Brain Initiative Stakeholder Group; and requiring a State Plan on Alzheimer's to be updated regularly. The intent of the legislation is to ensure that Maine remains committed to a public health approach to Alzheimer's and related dementia (ADRD) now and in the future, bringing our state in line with national best practices.

In 2024, very similar legislation introduced by Representative Margaret Craven was approved unanimously by this Committee and passed by the Legislature, but was held by the Governor and not signed into law, along with several other bills being reconsidered this year. We are grateful to Representative Dan Shagoury for continuing leadership on this issue and for the many bipartisan members of the Committee who have cosponsored this legislation.

Overview of the Alzheimer's and Dementia Public Health Issue

Alzheimer's is a progressive, fatal disease affecting 29,600 Mainers aged 65 or older. In addition, there are more residents who are living with other forms of dementia or who have younger onset Alzheimer's (when Alzheimer's occurs in individuals under the age of 65). In

Maine, the Alzheimer's Association estimates that 66,000 caregivers provide 102,000,000 hours of unpaid care for people living with Alzheimer's at a total value of \$2.9 billion.

As people live longer and the population ages, the prevalence of Alzheimer's will rise significantly in the coming years. Today, there are more than seven million Americans living with Alzheimer's, and \$384 billion is spent on their care, including \$297 million in MaineCare. By 2050, there will be about 13 million Americans living with Alzheimer's, costing \$1 trillion annually. This sharp rise will threaten federal and state budgets and our health and long-term care systems, as well as devastate individual families affected by Alzheimer's.

Given these significant challenges that lie ahead, what can be done now to mitigate the worst impacts? States must implement a public health approach to dementia that promotes risk reduction, supports early detection and diagnosis, and increases access to quality care and support for people living with dementia and their caregivers.

For example, research suggests that as many as 40 percent of all dementia cases worldwide could be prevented or delayed by addressing modifiable risk factors, such as diabetes, obesity, and smoking. In addition, the cost of ADRD can be reduced through early diagnosis. A 2018 analysis by the Alzheimer's Association estimated cost savings of \$63,000 per person when receiving a diagnosis earlier in disease progression, with \$30,000 in savings to Medicare, \$20,000 in savings to Medicaid, and \$13,000 in other savings.

History of Maine CDC Efforts to Address Alzheimer's Shows Inconsistent Focus

In 2011, Maine was one of the first states nationwide to take a serious look at addressing ADRD 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 state infrastructure dedicated to prioritizing these issues on an ongoing basis.

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. Maine's BOLD Act grant enabled it to establish an Alzheimer's Prevention Program and draft a new Maine's State Plan on Alzheimer's. As part of this process, Maine CDC convened the Healthy Brain Initiative 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 support, 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 craft recommendations.

In 2023, Maine's State Plan on Alzheimer's was finalized and released. Also in this 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 over five years. These efforts will therefore continue to benefit from additional federal funding over the coming years and should not have a fiscal impact on the current state budget.

L.D. 1677 Sustains Current ADRD Efforts over the Long-Term

Recognizing that ensuring the sustainability of efforts to address dementia in Maine is critical to achieving continued progress, one of the key recommendations is for Maine to codify an independent dementia advisory council as proposed in L.D. 1677. 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. It also reflects a best practice for public health, as promoted by the U.S. CDC through the BOLD program.

Maine Must Join Other States in Committing to Addressing ADRD

Several states have recognized on a bipartisan basis the significant value of formally establishing stakeholder groups to better address dementia. To date, 24 states have established such groups in statute, and there is pending legislation in other states in addition to Maine. Notably, Maine is the only state in New England without a form of permanent state infrastructure dedicated to addressing dementia, a glaring omission for the oldest state in the nation.

L.D. 1677 Leverages Non-Governmental Resources

The structure of the public health program proposed in L.D. 1677 is a cost-effective way to continue progress on ADRD in Maine. Notably, it does not rely solely on the Maine CDC to carry out these efforts, but rather leverages the engagement of the Healthy Brain Initiative Stakeholder Group to bring additional resources to the table. Implementation of several recommendations are led by stakeholder group members, such as the Alzheimer's Association. For example, in addition to leading efforts on L.D. 1677, we are also working to educate legislators on ADRD topics, promote state data collection on cognitive decline and caregiving, incorporate dementia response into hospital operational plans, and increase resources for dementia caregivers. Other organizations are leading efforts to improve

access to clinical trials in Maine, promoting quality care, and increasing access to dementia-focused training.

Conclusion

We are pleased that the Maine CDC has applied for and received BOLD funding to better address ADRD in Maine. They have done great work to bring partners together around a shared vision for improving the lives of those affected by ADRD and reducing future adverse impacts. There is strong support for this program federally, as evidenced by the recent bipartisan reauthorization of the program led by Senator Collins.

L.D. 1677 sustains these efforts over the long-term. We understand that the Department opposes the legislation on the basis it duplicates existing efforts, but the fact is that Maine CDC has walked away from a focus on ADRD before because it was not an ongoing legislated requirement. This bill has been drafted with intention to ensure it can be implemented within existing resources, not to add burdensome or costly requirements. For example, the state plan required by the bill has already been drafted and will not need to be updated until 2028.

On behalf of the tens of thousands of Maine families affected by dementia, thank you for your consideration of L.D. 1677. Again, we urge the Committee to support this critical legislation and stand ready to work with you on any changes necessary to ensure it can be signed into law this year.

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