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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

Joint Standing Committee on Health and Human Services

January 24, 2024

Maine Long-Term Care Ombudsman Program

Good afternoon, Senator Baldacci, Representative Meyer and Committee members, my name is Laura Harper. I am a Senior Associate at Moose Ridge Associates. I am here today to present testimony in support of this legislation on behalf of the Maine Long-Term Care Ombudsman Program.

As you know, the Maine Long-Term Care Ombudsman Program (LTCOP) provides advocacy for residents in nursing homes, assisted housing programs including residential care and assisted living. The program also advocates for home care and adult day services recipients. Additionally, patients in hospitals ready for discharge that encounter barriers in accessing long-term services and supports are provided advocacy by the Ombudsman Program.

This bill requires the Maine Center for Disease Control and Prevention to create an Alzheimer's Disease and Other Dementias Advisory Council, to examine the needs of individuals living with Alzheimer's disease and other dementias, the services available in the State for those individuals and the ability of health care providers and facilities to meet those individuals' current and future needs.

According to the Alzheimer's Association 2023 fact sheet, 29,000 Maine people aged 65 and over are living with Alzheimer's. This number is expected to grow, reaching 35,000 by 2025. There are an estimated 51,000 family caregivers in Maine providing care and assistance to individuals with Alzheimer's, these numbers are projected to continue to grow each year.

LTCOP hears stories from family caregivers daily, many who are trying to find resources for their loved ones with dementia so they can remain in their home as long as possible. Family caregivers often come up against numerous barriers in accessing the supports that are needed. Barriers such as staffing shortages, caps on respite programs, and limited adult day care centers put a massive strain on families. According to the Alzheimer's Association 2023 fact sheet, Maine families are providing 87,000,000 hours of unpaid care each year. Many of these caregivers are also trying to work full-time and care for their own young families. Once caregivers hit a wall, they are left with long-term care (LTC) facility placement or taking their loved one to the ER, both systems which are already overwhelmed.

LTCOP's hospital advocacy program assists those patients in the hospital who are facing a barrier in

accessing LTC placement or home care. Since the program started in 2016, the most common barrier to discharge has been challenging behaviors, which have most often been related to a diagnosis of Alzheimer's and other dementias. In 2022, LTCOP worked with 78 patients with challenging behaviors in the hospital waiting for LTC placement, of those patients, 48% had a dementia diagnosis. We hear countless first-hand stories from family members who face no other option but to bring their loved one to a hospital due to lack of resources when they become burned out. This puts a massive burden on the hospital system, as illustrated in the following stories:

LTCOP received a call from the daughter of a consumer with dementia. The consumer lived alone, his daughter lived a few hours from him and worked full time. The consumer was significantly confused, and it became unsafe for him to live alone. The consumer had a home care plan of care through the state funded Home Based Care program, but due to staffing shortages, his hours were not being staffed. The daughter asked for assistance with LTC placement, LTCOP began searching for placement closer to her. Before placement could be found, the consumer gained access to a car and drove out of state. The consumer was picked up by police, very confused, he was brought to a local ER where it was determined he could not return home without 24/7 supervision. The consumer waited in the hospital until placement was found.

LTCOP received a call from the son of a consumer with dementia. The consumer was living at home alone, her son worked full time but attempted to visit his mother multiple times a day to check on her. The consumer's neighbors found the consumer wandering outside confused on multiple occasions. The consumer had a Section 19 home care plan of care, but only half of it was staffed. The consumer's son was overwhelmed and burned out, he requested LTCOP's help to find a LTC placement. Before placement could be located, the consumer was found outside having fallen, she was taken to the hospital where she remained until placement was found.

Appropriate dementia diagnostic and treatment services can also be difficult for consumers and families to locate. LTCOP hears stories from families stating they have a loved one with severe cognitive decline, but no clinical diagnosis. Some are on wait lists for assessments and others live in rural areas where transportation remains a barrier. Not having a correct diagnosis delays a family's ability to find the appropriate long-term services and support as well as family caregiver training. LTCOP observes families not able to access a diagnosis for their loved one until they reach the point of needing to go to the hospital. There is a clear need for early diagnostic and treatment resources, especially in rural areas of our state.

Bringing together stakeholders to identify trends and use data-driven evidence to advise on needed resources and policy changes for our state will be of significant value to Maine caregivers. It is critically important that we address this public health crisis effectively through comprehensive planning and policy making to address the needs of individuals with Alzheimer's and other dementias, along with their family caregivers, now and into the future. The establishment of the Advisory Council will provide a forum to do that.

Thank you for your consideration.