

Support Services For People With Disabilities

Kristin Overton Chesterville, ME

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Senator Baldacci, Representative Meyers, and honorable members of the Health and Human Services Committee:

My name is Kristin Overton and I am the Executive Director of SKILLS, Inc, a Board Member of MACSP, and a member of the MACSP Legislative Committee. I sit on the OADS Lifespan Provider Stakeholder Committee, the Maine Essential Care & Support Workforce Partnership Advisory Committee, and prior to my time at SKILLS, devoted 16 years to the Aging Network at an Area Agency on Aging. I am here today to testify in favor 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*

SKILLS is a non-profit organization in central Maine, serving adults with intellectual and developmental disabilities for more than 60 years. SKILLS provides more than 120 people with 24/7 residential support, employment services, and day programming under Sections 21, 29, and 97-F. More than 60% of the people that SKILLS supports are over 45 years of age. Adults with intellectual and developmental disabilities experience incidences of dementia at rates up to five times higher than older adults in the general population"ⁱ. Dementia onset is experienced much earlier and much more rapidly in adults with intellectual and developmental disabilities and those with down syndrome often experience onset in their 50's.

I am happy to support this bill which establishes the 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. Please do not forget about the members in our community with dementia who also have an intellectual or developmental disability and for whom a transition in living arrangement to an institutionalized setting is exponentially more difficult; often made even more so for those who experienced institutionalization at Pineland Farms and/ or due to long-term care staff who do not have training and experience supporting those with IDD. The HCBS Settings Rule and other licensing regulations can make it extremely challenging for providers to offer dementia-friendly long-term care to residents living in family-style group homes or Shared Living arrangements and the system often cannot respond quickly enough for exceptions due to the accelerated decline from diagnoses to mid-to-late-stage dementia for those with IDD – often experienced in months rather than years. As a provider, it breaks our heart to watch a long-term resident experience this slide knowing that we are often handcuffed by regulations which means we cannot present the safe environment and adequate staffing levels required to allow them to age in place.

LD 2125s Advisory Council and the information and action plan its members will present is critically needed to understand the vastness and impact that dementia and Alzheimer's' has on all members of the





community and I thank Representative Craven and all the other co-sponsors of the bill for bringing this bill forward.

I urge you to pass LD 2125 and I'm happy to answer any questions or to further discuss the necessity of a more complete and broader view of dementia and Alzheimer's on members of the IDD community.

Respectfully,

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¹ Strydom A, Chan T, King M, Hassiotis A, Livingston G. Incidence of dementia in older adults with intellectual disabilities. Res Dev Disabil. 2013 Jun;34(6):1881-5. doi: 10.1016/j.ridd.2013.02.021. Epub 2013 Apr 9. PMID: 23578903.