

Thank you so much for this opportunity to speak on S.206. My name is Meg Polyte and I am the Policy Director for the Vermont Chapter of the Alzheimer's Association. I'm here to testify in support of S.206 and to provide some context on the impact of Alzheimer's Disease and related dementias in Vermont and on Vermonters. I hope by sharing specific data and trends, it will assist you in identifying how S.206 can begin to mitigate some of our challenges and where it might be strengthened.

Alzheimer's is a public health crisis in the USA and here in Vermont. Right now, there are more than 13,000 Vermonters over the age of 65 living with Alzheimer's. That number is projected to climb to 17,000 by 2025. We know these numbers don't capture all Vermonters living with dementia; they miss those like Pamela with Younger Onset, Alzheimer's is often under diagnosed, and there is a great stigma with diagnosis which leads to some people not obtaining a diagnosis. One in three seniors dies with Alzheimer's or another dementia. It kills more than breast cancer and prostate cancer combined and is leading cause of disability and morbidity in older adults. It is the 5<sup>th</sup> leading cause of death in Vermont and we have no cure.

As the prevalence of Alzheimer's disease increases, so does the need grow our paid workforce including Primary Care Physicians, specialists such as geriatricians and neurologists for diagnosis, registered nurses and physical therapists to treat people through the course of this disease, and members of the direct care workforce such as home health aides and personal care aides to assist with activities of daily living. In 2021, we had 9 geriatricians, we need a 255% increase to meet demand in 2050. We need a 31% increase in personal care aides to meet demand in 2028.

Constant turn-over and understaffing puts additional stress and workload on caregivers who remain in the workforce. According to the Bureau of Labor Statistics, the median income of home health and personal care aides in 2020 was \$27,080, slightly less than the median income of a retail worker, who has no health care responsibilities. The connection between low wages, turnover, and lack of staffing are clear.

Both paid and unpaid caregivers require our attention. They have difficult jobs and many do not receive adequate training to provide dementia care or support a person with Alzheimer's as they move through the stages of this disease. Societal respect for all caregivers, and the vital role they play, falls woefully short.

In 2021 Vermont had 26,000 unpaid caregivers supporting family members with Alzheimer's and other dementias. The value of that unpaid care was \$758 million dollars. Approximately two-thirds of caregivers are women; more specifically, over one-third of dementia caregivers are daughters. Approximately one-quarter of dementia caregivers are 'sandwich generation' caregivers, meaning they care for an aging parent and at least one child.

Unpaid caregivers for those with dementia carry a particularly heavy burden.

- Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties.
- 74% reported they were somewhat or very concerned about maintaining their own health since becoming a caregiver.
- They are twice as likely as caregivers for individuals without dementia to report completing medical/nursing related tasks was difficult and they often lack the information or resources to manage complex medication regimens.
- Caring for someone with dementia has a long duration and the amount of time required increases as dementia progresses. One study showed that people with dementia required 151 hours of care per month at the onset of dementia and 283 hours per month eight years later. That is 5-9 hours of care a day; before, after or during work.
- In 2020, 60% of unpaid dementia caregivers were employed and they worked an average of 35 hours a week. 57% reported sometimes needing to go in late or leave early due to caregiving responsibilities. 18% reduced their work hours due to caregiving responsibilities.
- In 2021, unpaid caregivers spent approximately \$12,400 on out-of-pocket expenses for the person with dementia. This is about twice what is spent when caring for someone without dementia. Further, 4 in 10 caregivers indicated the “food they bought just didn’t last,” and 3 in 10 reported eating less because of care related costs.

These are just some of the daunting statistics provided in the 2022 Alzheimer’s Disease Facts and Figures report released last month. The problem looms large and will require ongoing collaborations, workforce investments, and focus to, as DAIL’s mission states; “Make Vermont the best state in which to grow old or to live with a disability - with dignity, respect and independence.”

S.206 will not solve all the challenges I have presented, but it is an important start and provides a plan to create some of the infrastructure we will need to be successful.

Last month I was elected Chair of the Governor’s Commission on Alzheimer’s Disease and Related Disorders (ADRD.) It is an honor to step into this role and I’m committed to expanding the impact of The Commission’s work. S.206 will help with that because it gives some explicit authority to the ADRD and will help leverage the expertise of ADRD members. In January, your committee was provided the ADRD Annual Report, which contains our 2022 Legislative Priorities as well as the projects we will focus on this year. Our two primary goals are creating a dementia-capable workforce, and finding short- and long-term solutions to the extreme workforce shortages across all care settings. We also have a subcommittee addressing racism directed at professional caregivers and another that is working on creating a Dementia Friendly Vermont.

I strongly support the language in S.206 that requires the ADRD to, not only help create the State Plan on Aging as it relates to Alzheimer's, but to evaluate it and make annual revisions as needed. I believe embedding the Action Plan on Alzheimer's and Aging into the State Plan on Aging that is required by the Older Vermonter's Act makes a lot of sense and will ensure the plan is updated on a regular basis. I hope that by coordinating the plans we will see more utilization and be more efficient in the planning process. As a participant in the creation of both the State Action Plan on Alzheimer's and the State Plan on Aging, I can confirm many of the partners are similar and there is a lot of overlap in our goals.

In 2016, the Commission began a process of reviewing rules and regulations governing long-term care facilities, specifically the training provided to direct care staff who work with Vermonters living with dementia. At the end of 2018, they issued recommendations for the development of regulations regarding dementia care training for staff working in long-term care facilities in Vermont. Unfortunately, COVID interrupted implementation of this work.

I support the Professional Education Opportunities Report required by S.206 and it aligns with the priorities of the ADRD, but I'm concerned we may not have sufficient resources to do justice to this task. The bill specifically calls out the need for a dementia-capable workforce with regard to health care and human services providers and first responders, but as you heard from previous testimony and in some of the data I shared, dementia informed education and training are needed across many sectors. The Committee may decide it is important to identify some of the sectors missing and include that language in the bill. For instance, unpaid caregivers, law enforcement, transportation providers, agencies that privately contract personal care aides, and general staff in any medical office or care facility, the list could be endless. I look forward to appointing members to a work group to take on this task, and recognize we are empowered to consult with relevant stakeholders, but I am concerned about capacity if we have no staff support or resources to do this vital work.

Finally, I would like to speak to the BOLD grant and expansion of programs that is currently happening. I applaud Rhonda and Angela for recognizing the need for coordinated activities, launching the Hub and Spoke model for dementia care, creating the Alzheimer's and Healthy Aging Working Group, and working so diligently to integrate the needs of Vermonters with dementia and caregivers into current programs. It is clear both staff and leadership of the Department of Health and the Department of Disabilities, Aging and Independent Living recognize the impact of this disease and are committed to finding ways to leverage the resources available to address many of the needs. That said, this work, and Vermonters with Alzheimer's, need a dedicated point person to oversee and coordinate the many integrated programs required to address dementia.

The BOLD grant we received is specifically to build our infrastructure and we are making notable progress, but infrastructure requires maintenance. As educational requirements are

established we will need someone to help evaluate if they are being met and what the impact has been. You heard from the advocates about the extreme difficulty of finding resources and the need for a centralized location for information. We need a full-time Alzheimer's Disease Coordinator. Not only will this position ensure the programs that we have started will continue, it will show the CDC our commitment to addressing dementia and to establishing the infrastructure needed to be successful.

Vermont is the third oldest state, by median age, and the prevalence of this disease is on a steep, upward trajectory. In 2022, the total national cost of caring for people with Alzheimer's and other dementias is projected to reach \$321 billion. This does not include the more than \$271 billion in unpaid caregiving. Alzheimer's is one of the most expensive diseases for our state and for those who have it. We must act now to ensure we have sufficient capacity to diagnose and care for those with this disease. S.206 is the first step in this process.

On behalf of Vermonters with Alzheimer's and their families and caregivers I thank you for dedicating your time to this cause and look forward to collaborating with you in this endeavor.