

State of Vermont

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Agency of Human Services

To: The House Committee on Human Services
From: Angela Smith-Dieng, Director of Adult Services, DAIL
Date: April 6, 2022
Re: Testimony on S.206, an act relating to planning and support for individuals and families impacted by Alzheimer's Disease and related disorders

Thank you for taking up the important topic of addressing Alzheimer's Disease and related dementias (ADRD) today. This effort aligns well with the mission of DAIL, which is to make Vermont the best place to grow old or live with a disability, with dignity, respect and independence, and also aligns with the principles of the Older Vermonters Act passed in 2020 to make Vermont an age-friendly state.

Over 13,000 Vermonters are currently living with Alzheimer's disease, a number expected to increase 30% by 2025. Alzheimer's is the 5th leading cause of death in Vermont. Over 25,000 Vermonters provide family caregiver support to those with dementia, often for many years at a time. As you have heard from other witnesses, the impacts of dementia are significant to individuals, families, our healthcare system and long-term care system.

In 2020 DAIL conducted a survey of family caregivers as part of the needs assessment for the State Plan on Aging. Results showed that caregivers of people with Alzheimer's or dementia reported significantly greater negative impacts from caregiving, including impacts on physical health, physical activity, emotional health and sleep. Negative impacts were highest among those who provided 24/7 care.

DAIL serves many people with Alzheimer's and dementia across our divisions and through our services, programs and network of providers, including through both Choices for Care and Older Americans Act programs. Choices for Care includes a cognitive screening as part of the clinical assessment which determines the level of support an individual may need. Choices for Care provides services such as respite, companionship, and Adult Day, to support both the individual and caregiver. There is the option to have care provided by an agency or to self-direct care, in which case a family member can be paid to provide services to their loved one.

The Older Americans Act includes Title III-E, the National Family Caregiver Support Program, which includes funding to the Area Agencies on Aging for family caregiver support, including a range of services such as assessment, information and assistance, education, training, counseling and respite. With a recognition that respite is key to caregivers being able to keep their loved ones at home, DAIL uses state general funds to provide additional Dementia Respite Grants to

caregivers of Vermonters with dementia not eligible for Choices for Care; these grants are distributed through the Area Agencies on Aging.

I've included a map with my testimony that shows the variety of supports currently available across Vermont, including AAAs, Adult Days, Memory clinics and Memory cafes, counseling, education, and support groups.

Current Initiatives

In addition to these ongoing supports, there is a great deal of good work and collaboration underway to address gaps and better serve people with ADRD in our systems of care. A few initiatives I want to highlight today:

- DAIL and the Department of Health co-facilitate an ADRD 'Hub & Spoke' workgroup of healthcare leaders with a focus on increasing early detection and diagnosis at the primary care level. This group has developed multiple types of education for Primary Care Teams. The goal is to support PCPs with making a diagnosis at the local level and reducing the waiting list to be seen at the UVM Memory Program; simultaneously, with more knowledge of local resources, PCPs will then also be able consistently to refer family caregivers to community resources for support.
- DAIL has worked with the Area Agencies on Aging (AAAs) to disseminate an evidence-based caregiver assessment tool called TCARE to better identify caregiver stress, burden and individualized needs and connect caregivers with resources such as counseling, education and training, respite, etc. This assessment will allow a deeper and more individualized understanding of each caregiver's experience in order to connect them with the most appropriate resources to meet their needs. Research shows that the use of TCARE can delay the need for facility care by 18 months.
- Through a grant from the CDC, the Department of Health (VDH) is working on a new Action Plan on Alzheimer's, Related Dementias and Healthy Aging, which includes goals related to risk reduction, increased public awareness, improved early detection and diagnosis, and more. The development of this plan has included many stakeholders, will include measurable goals and strategies, leverages key partnerships and initiatives, and will be finalized this year. I'll note that this plan will be added as an addendum to our forthcoming 2023-2026 State Plan on Aging as we work together to integrate efforts and build on our collaborative work.
- A major priority at DAIL right now is on workforce recruitment, retention and training. As it relates to ADRD, we want to ensure we have the workforce necessary to serve all those in need across the continuum of care settings and to build a more dementia-capable workforce, meaning that all those who work with people with dementia have the knowledge, skills and competencies to provide quality care and services. Our goal is to leverage current programming and additional funding opportunities as they become

available (for example, enhanced FMAP funding, federal grants from the Administration on Community Living, etc.) to expand and strengthen supports for people with dementia and their caregivers across Vermont.

Comments on S.206:

DAIL is supportive of S.206 in seeking to better address the state's response to ADRD to support people living with dementia and their caregivers. With our changing demographics, this is an important goal and deserves real focus. I have just a couple comments on specific sections of the bill:

- Section 2 (page 7) includes a requirement that the State Plan on Aging address ADRD in a number of ways; DAIL can certainly incorporate this focus into the next plan and is appreciative of the effort to have a more integrated plan. I'll note that this does not include additional funding to address ADRD, so any goals or strategies will be limited by available resources and will most likely need to be incremental in their approach. This same limitation also applies to Section 4 (page 10) which includes a requirement for VDH and DAIL to develop and maintain public education materials.
- Section 5 (page 11) requires that DAIL and VDH submit a plan to the legislature "to fund a permanent Alzheimer's Disease Coordinator position." DAIL would recommend removing the word "permanent" from this sentence. By removing 'permanent' the departments would have more flexibility in planning for a position, since federal grant funds can be used for limited-service positions but not permanent positions.

Additional Resources:

[Governor's Commission On Alzheimer's Disease and Related Disorders \(ADRD\) | Adult Services Division \(vermont.gov\)](#)

[Brain Health, Alzheimer's Disease and Dementia | Vermont Department of Health \(healthvermont.gov\)](#)

[2020 Needs Assessment of Vermonters Age 60+ And Their Family Caregivers.pdf](#)

Attached: Family Caregiver Support Map

ADRD Information and support can be found within a growing network of organizations throughout the state.

As of Fall 2021:

Program and services that are offered through the AAAs are:

T-Care assessment, 'Powerful tools for Caregivers' training, Self-care and Stress management workshops, support groups, funds to provide respite in home, at an Adult Day program or short-term facility respite, funds for supplemental services such as – meal preparation, light housework, transportation to/from medical appointments, adaptive technology, home modifications for safety and access. **ALL core OAA services are available for Individuals living with Early Onset ADRD diagnosis.**

Alzheimer's Association offers 24/7 statewide Phone support, online education programs and training, in person and online support for individuals with ADRD and their caregivers.

UVM Memory Center offers diagnostic and treatment services as well as support, education, and training using the 'Carers' program.

The Memory Clinic in Brattleboro offers diagnostic and treatment services and referrals to counseling and support groups

Clinical Counseling for Caregivers: SVCOA has embedded a counselor in their office that focuses on caregivers and the emotional challenges they face in that role.

Caregiver Coalition: Rutland's Caregiver Coalition represents efforts of a diverse group of agencies, private, public, professional, non-profit, and for profit that serve caregivers by identifying and addressing their needs through collaboration in order to improve the overall quality of life for Caregivers, their families and the community.

Dementia Friendly Communities: St Albans and Newport are 2 cities that have made a commitment to start implementing tools to make their communities accessible/ 'friendly' for individuals living with ADRD.

Gifford Hospital in Randolph has created a memory clinic.

