Report to The Vermont Legislature

Annual report of the Commission on Alzheimer's Disease and Related Disorders

For Fiscal Year 2018

In Accordance with 2015 Act 028, an Act related to the membership of the Commission on Alzheimer's Disease and Related Disorders

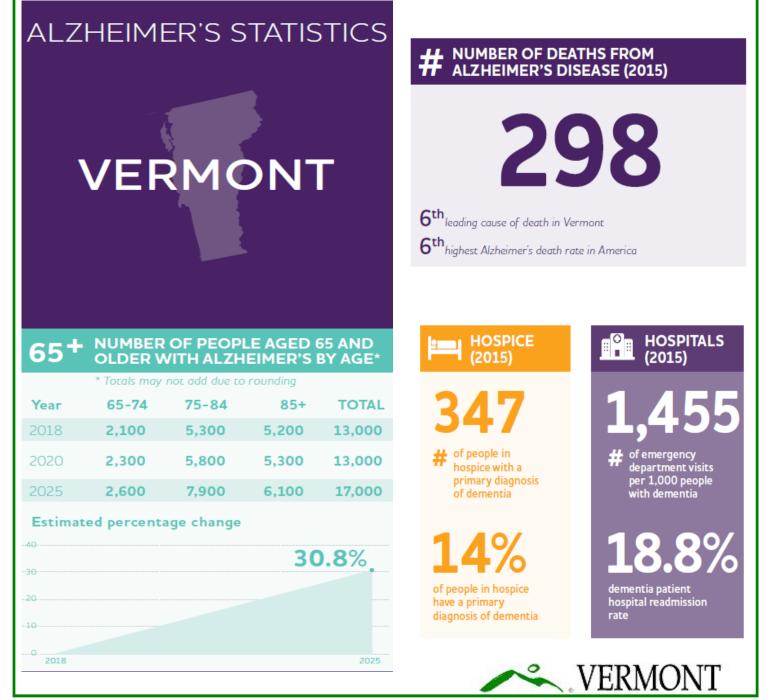
Submitted to:	Senate Committee on Health and Welfare House Committee on Human Services
Submitted by:	Martha Richardson, Chair Commission on Alzheimer's Disease and Related Disorders
Prepared by:	Martha Richardson, Chair Commission on Alzheimer's Disease and Related Disorders
Report Date:	January 15, 2019



AGENCY OF HUMAN SERVICES Department of Disabilities, Aging and Independent Living Governor's Commission on Alzheimer's Disease and Related Disorders
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Overview: The State of Alzheimer's and Dementia in Vermont

PREVELANCE: Over 13,000 Vermonters age 65 and older are living with Alzheimer's Disease in 2018. By 2025 this number is estimated to increase by 30.8% to 17,000.



Cost of Care in Vermont:

Medicare spent \$20,664 per capita on people dementia in 2017.

Medicaid spent \$106 million on people with dementia in 2017.

Medicaid costs to care for people with dementia are expected to increase 36.1% by 2025.

CAREGIVING (2017)

30,000 Number of Caregivers

34,000,000 Total Hours of Unpaid Care

\$430,000,000 Total Value of Unpaid Care

\$27,000,000 Higher Health Costs of Caregivers



Over 5 million Americans are living with Alzheimer's, and as many as **16 million** will have the disease in 2050. The cost of caring for those with Alzheimer's and other dementias is estimated to total \$277 billion in 2018. increasing to \$1.1 trillion (in today's dollars) by mid-century. Nearly one in every three seniors who dies each year has Alzheimer's or another dementia.



Recommendations for Legislative Action in 2019

The ADRD Commission recognizes the inherent challenge in this work. These are complicated diseases and require a coordinated, multi-pronged approach and a public-private partnership to address effectively. As a state, Vermont must have long-term goals and plans that include collaboration at all phases and levels. While working on the long-term vision of a world without Alzheimer's, the ADRD Commission believes that the following short-term recommendations are critical to our success:

1. SUPPORT PUBLIC UNDERSTANDING OF ALZHEIMER'S & DEMENTIA WITH \$150,000 TOWARD A PUBLIC HEALTH CAMPAIGN ON BRAIN HEALTH AND DEMENTIA AND FUNDING FOR DEDICATED STAFF:

With a growing body of research showing the importance of physical activity, mental stimulation, and social activity in building a cognitive reserve, as well as the critical need for early detection and diagnosis, **now is the time to educate across the lifespan and across sectors**. DAIL and VDH have built a collaborative relationship over the last two years focusing on efforts to address challenges of ADRD but resources are limited. With the addition of a dedicated shared staff person, this work can achieve a bigger impact through more focused, sustainable initiatives.

2. INCREASE SUPPORT FOR FAMILY CAREGIVERS WITH AN ADDITIONAL \$100,000 FOR EDUCATION, TRAINING AND RESPITE:

Family caregiver training, psycho-social support and dementia respite grants help reduce caregiver stress, improve care skills and support people living with dementia to remain at home. In states where caregiver assessments and person centered plans have been implemented, studies have shown that family caregiver stress and burden is reduced up to 84%. The local supports allow caregivers to keep their loved ones at home longer, delaying nursing home placement for 18-24 months. *With the success of family caregiver support, states have seen a reduction of 20% in Medicaid services, resulting in estimated \$10 million in savings of state and federal dollars.*

3. PROTECT MEDICAID: Medicare does not pay for long-term care services; Medicaid is the only funding source for long-term care for thousands of Vermonters with Alzheimer's and dementia. For these Vermonters, every service provided, from personal care assistance to assistive technology to adult day and respite care, is critical to maintaining safety and quality of life while living with dementia. Whatever changes to Medicaid might be made at the federal level, *it is critical that the State of Vermont maintain its strong commitment to funding Medicaid to provide high quality services and supports for people living with dementia in facilities and in community.*

In addition to the recommendations above, the Commission encourages the legislature to revisit the recommendations in the 2008 Vermont State Plan on Dementia. While the scope of the challenge has increased over the last decade, and some good progress has been made, many of the recommendations still apply and have become more critical today.



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OUR CHARGE IN VERMONT:

Alzheimer's is a public health issue that needs a coordinated and comprehensive response. Vermont is the second oldest state in the nation (by median age), with one in three Vermonters expected to be over 60 by 2030 and those over 80 expected to double. People are living longer but with more chronic and complex health conditions, Alzheimer's and dementia among them. Vermont currently lacks the capacity to adequately support the growing number of individuals with Alzheimer's or dementia and their families. We must do more to educate around prevention, expand and strengthen our workforce, and engage our decision makers if we are to be prepared to meet the needs of Vermonters now and into the future. The Governor's Commission on Alzheimer's Disease and Related Disorders (ADRD) is proud to play a role in this critical effort. We focus on 1) increasing awareness of the disease, with a focus on early detection, 2) advocacy for resources and training of providers across the continuum of care, and 3) supporting the growing number of family caregivers. Below are highlights of the Commission's work in 2018:

ADVOCACY, PUBLIC AWARENESS, EDUCATION/TRAINING:

Despite rising concern regarding the increasing prevalence of ADRD and the growing healthcare costs associated with the disease, significant stigma and misunderstanding still exists. It is critical that our state develop the knowledge and understanding needed to address the needs of those impacted today and in the future.

- In 2018 the Commission researched successful models that could be implemented to improve dementia specific training in Vermont. The Commission submitted recommendations based on these models to the Department of Licensing and Protection to consider regulation changes that can increase and enhance dementia training statewide resulting in improved quality of care.
- Commission members hosted and participated in Alzheimer's Awareness and Advocacy Day at the Statehouse on March 2, 2018, and members met with their senators and representatives to share their stories and raise awareness.
- Commission members provided information, resources and stories to the Burlington Free Press for a 5 week series focused on brain health and ADRD.
- Commission members participated in a series of listening sessions with the Attorney General's office around the topic of Dementia training for first responders and at the Police Academy.



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ADVOCACY, PUBLIC AWARENESS, EDUCATION/TRAINING (CONTINUED):

- DAIL and Commission members participated in an awareness event titled: *Every Second Counts*. DAIL Commissioner, Monica Hutt and Department of Health Commissioner Dr. Mark Levine were panelists for a discussion following a documentary viewing.
- Commission members were also invited as guests to discuss Alzheimer's and dementia on 'Across the Fence,' a public radio show that has a audience of 20,000 older Vermonters.

PREVENTION, EARLY DETECTION AND DIAGNOSIS:

For years Alzheimer's and dementia have been viewed as diseases of older individuals and rarely addressed until chronic symptoms begin to affect activities of daily life. However, research continues to emphasize the importance of early intervention to allow families the time to plan and prepare for future needs.

- Vermont Department of Health (VDH) and DAIL have implemented an Alzheimer's Action Plan. The
 Departments developed a plan that included Grand Rounds education on dementia, including its
 links to chronic disease, such as vascular risk factors; increased media focus on Healthy Brain
 Month; and workforce development/training for those interacting with people with dementia. VDH
 and DAIL used <u>The Healthy Brain Initiative: A National Public Health Road Map to Maintaining
 Cognitive Health</u>, developed by the CDC, as a guiding tool.
- At the Grands Rounds, a state wide 'hub and spoke model' was proposed by a partnership between One Care and UVMMC as an approach to diagnosis and support for ADRD patients and their caregivers.
- Also at the Grand Rounds, UVMMC Memory Center proposed dissemination of a screening method called the 'Vermont Mini-Cog.' The VT Mini-Cog surpasses the MMSA and MoCA in brevity, sensitivity, and acceptability; it does not need any special equipment and can be administered in three minutes. It has been proven effective in diverse populations regardless of age, socioeconomic status or education level.



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ENHANCING CAREGIVER SUPPORT:

National and state information indicates that as many as half of families receiving a dementia diagnosis receive little or no information or support for addressing the disease and its impact on the person and their family. The Commission is working to combat this trend.

- This Year the Commission advocated for the State Plan on Aging to include a focus in the plan narrative on ADRD trends as well as an objective to support caregivers.
- UVM Memory Center hosted a Gerontology Symposium that offered a Family Caregiver track with featured workshops on role of the caregiver and cognitive therapeutics. As well as a presentation for professionals on Dementia, Depression, and Mild Cognitive Impairment.
- Commission members participated in a Healthy Aging Conference at Killington Grand Hotel in October. ADRD relevant presentation topics included: Aging Network, Providing support in the home and community, Multi-disciplinary approach to ending abuse in later life, and Writing our way through Caregiving.
- Commission members submitted editorial articles published in six Vermont publications to raise awareness about November as National Family Caregivers Month.
- This year DAIL is piloting a Caregiver Assessment for recipients of the State Dementia Respite Grant. This Assessment creates a caregiver profile and collects information on caregiving skill level, needs, and measures stress/burden. The intention of this assessment is to determine areas of greatest need and assist Caregiver support Coordinators at the Area Agencies on Aging to create a personalized service plan to support caregivers.



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Commission Membership

NAME (alphabetical by last name)	REPRESENTATION
Mohamed Basha	Registered Nurse
Mark Boutwell	Area Agencies on Aging
Senator Randy Brock	State Senate
Alecia Demario	Nursing Home Administrator
Molly Dugan	SASH
Grace Gilbert-Davis	Alzheimer's Association
Glenn Jarret	Legal profession
Paula Johnson	Family Caregivers
Jeffrey K. Kelley	Clergy
Alexandra Messerli	Physicians
Representative Dan Noyes	State Legislature
Janet Nunziata	UVM Center on Aging
Diane Olechna	Home Health
Roberta Rood	Mental health provider
Angela Smith-Dieng	Dept of Disabilities, Aging & Ind Living
Andrea Stauffenecker	Adult Day Provider
Joyce Touchette	Residential Care
Rhonda Williams	Department of Health
Current Vacancies:	
Business Community	In process of seeking applications
Social Workers	In process of seeking applications



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References

1. <u>Caregiver Statistics: Work and Caregiving</u>, Family Caregiver Alliance, 2016 (https://www.caregiver.org/caregiver-statistics-work-and-caregiving).

2. <u>A Statewide Survey: Caring for Caregivers in Vermont</u> (http://asd.vermont.gov/sites/asd/files/ documents/2017%20Caregiver%20Survey%20Report%20-%20Kelly%20Melekis.pdf), July, 2017.

3. <u>Alzheimer's Association 2018 Facts and Figures</u> https://www.alz.org/alzheimers-dementia/facts-figures

4. <u>State of Vermont Action Plan on Alzheimer's and Health</u> http://www.healthvermont.gov/sites/ default/files/documents/pdf/HPDP_ActionPlanonAlzheimersandHealthyAging.pdf

5. <u>CDC Healthy Brain Initiative: Road Map</u> https://www.cdc.gov/aging/pdf/2018-2023-RoaMap-508.pdf

6. Washington State research Caregiver Assessment and Planning https://www.dshs.wa.gov/altsa/

stakeholders/caregiver-assessment-and-planning-tcare

7. ADRD Commission Dementia Training Recommendations https://asd.vermont.gov/governors-

commission-adrd

