

# Governor's Commission on Alzheimer's Disease and Related Disorders 2021 Annual Report ~ January 15, 2022

## Recommendations for Legislative Action in 2022

For 2022, The Governor's Commission on Alzheimer's Disease and Related Dementias (ADRD) is recommending a focus on two primary goals:

- Creating a dementia-capable workforce
- Finding short- and long-term solutions to the extreme workforce shortages across all care settings – from homes to skilled nursing facilities.

We support three action areas to achieve these goals:

1. Improve the ability of those who provide care in all settings – home- and community-based and long-term care facilities – to grow and retain their workforce.

Specific requests:

- Increase the state's investment in home and community based Choices for Care (CFC) including Assistive Community Care Services (ACCS) program rates by \$6 million in SFY 2023.
  - Implement workforce recommendations from the Health Care Workforce Development Strategic Plan (published October 15, 2021). Include unlicensed direct-care workers in recommended actions pertaining to financial incentives, education and training and recruitment and retention.
  - Pass H.153, An Act Relating to Medicaid Reimbursement rates for home- and community-based service providers. Establish a rate schedule that provides reasonable and predictable rates for CFC home- and community-based services and ACCS that reflect cost growth.
2. Require evidence-based, dementia-specific training for all staff who care for and interact with Vermonters with dementia to improve quality of care.
  3. Expansion: Expand access and coordination of current services and supports across the state.

## BACKGROUND

The number of older Vermonters with Alzheimer's disease is estimated to increase **more than 30%** by 2025 - from 13,000-plus Vermonters today to 17,000 in **just four years**.

Vermont is one of the top five oldest states (by median age), with one in three Vermonters expected to be 60 or older by 2030, and the number of those over 80 expected to double in that time.

Vermonters are living longer but experiencing more chronic and complex health conditions, Alzheimer's and dementia being foremost among them. (See Page 5 for statistical graphics.) The Commission's long-term goal is to enable and support a high-quality, sustainable and robust coordinated system of services and supports to meet the needs of the thousands of Vermonters living with Alzheimer's now and in the future. Extensive groundwork for achieving this goal has been underway for two years, in broad constituencies (including primary care providers), through the CDC BOLD grant, whose objectives are to change systems and environments to increase rates of early detection, risk reduction, caregiver support and reduction in avoidable hospitalizations related to co-morbidities.



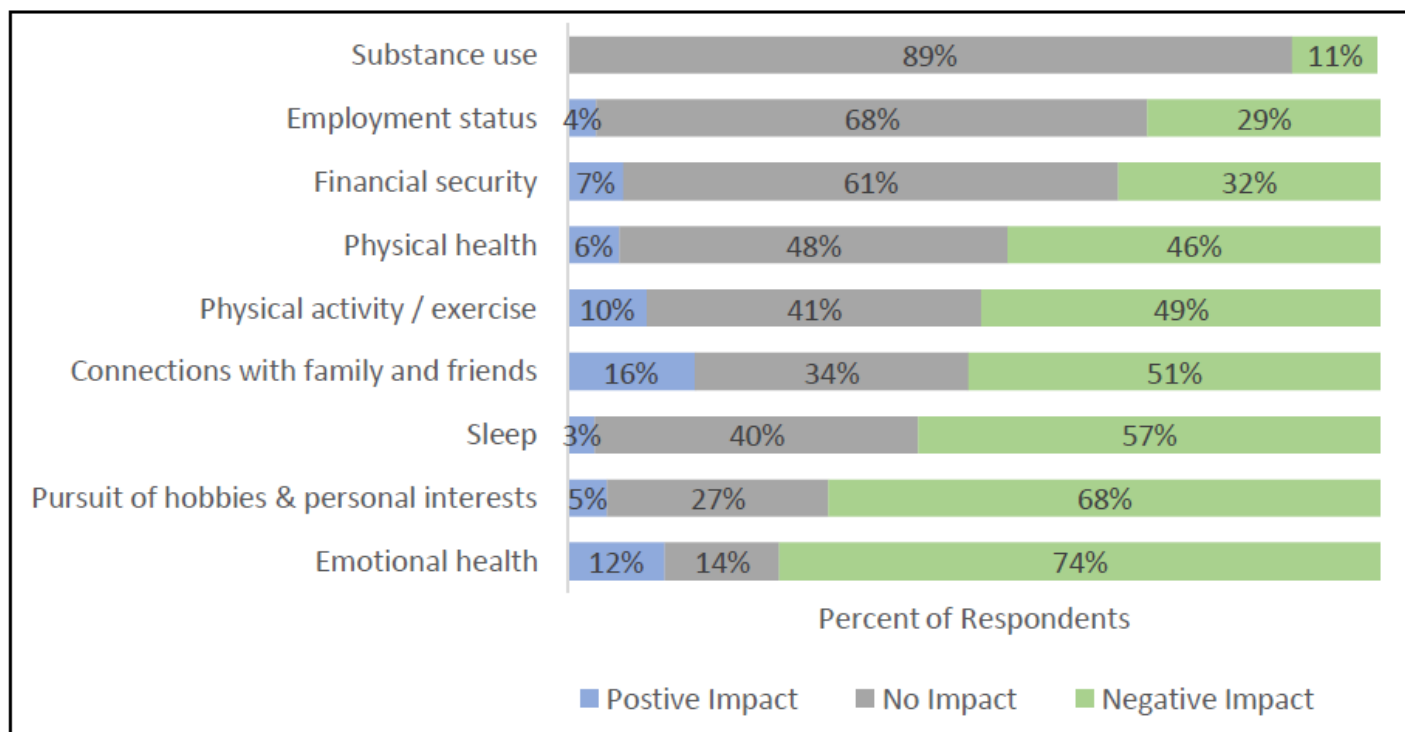
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## CAREGIVING IN VERMONT

In 2020, the VT State Unit on Aging (SUA) completed a [survey](#) of older Vermonters (60+) and unpaid family caregivers for individuals 60+.

- 41% of caregivers responding to the survey care for a family member with Alzheimer's or other form of dementia.
- Adult children, as compared to spouses, give care to older adults. Other relatives most often care for oldest persons receiving care.
- The majority of caregivers have been providing care to family member for more than a year.
- Over half of the family caregivers report providing care for more than 20 hours a week. 28%, more than one-quarter, provide care seven days a week, 24 hours a day.
- Survey respondents were asked to consider a list of possible impacts, (see Figure 42).
- Caregiving has the greatest negative impact on emotional health, and the opportunity to pursue individual interests.

**Figure 42: Impact of Caregiving**



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## Addressing Racism Directed at Professional Caregivers

In 2021, a Commission subcommittee was created to address press reports of BIPOC professional caregivers subjected to racism via verbal and physical abuse by care recipients experiencing cognitive decline. Subcommittee discussions have included administrators from residential facilities and home health agencies across the state, and have used resources from the VT Racial Equity Advisory Council. As the discussion continues, stakeholder input will be vital in developing guidance and recommendations to be disseminated statewide.

The Commission's goals are to:

- Support the caregivers essential to the trained workforce Vermont desperately needs.
- Ensure that individuals experiencing cognitive decline (and hostile behaviors that sometimes emerge as a result) have access to the care they need in a no/low-conflict environment.

The subcommittee's work on this issue in 2022 will focus on two areas :

1. **Training:** How Vermont can ensure that staff (even those temporary/traveling) are trained in dementia basics, communication with someone experiencing cognitive decline, and de-escalation.
2. **Policy/procedure development and implementation at executive/management level:** What can realistically be put in place to protect staff from abuse, and ensuring that staff are told how to report and other procedures to expect when an incident occurs.

The commission is committed to developing guidance that will ensure all caregivers are provided a safe, supportive, and Diversity, Equity and Inclusion (DEI)-informed workplace.

## Creating a Dementia Friendly Vermont

The Commission resumed efforts started in 2019 to be recognized as a Dementia Friendly state by [Dementia Friendly America](#) (DFA). Focus in the pandemic shifted to public awareness and Home and Community Based Services (HCBS). Success requires establishing statewide Dementia Friendly practices to support individuals living with ADRD and their caregivers.

One of the first outcomes of this work will be [Dementia Friends](#), sponsored by UVM Center on Aging and the state's five Area Agencies on Aging. In 2022, the Commission will focus on implementing Dementia Friends across the state, introducing DFA resources to municipalities and organizations ready to commit to becoming dementia-capable.

(Activities continued on page 4)



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## Action Plan on Alzheimer's and Healthy Aging

The ADRD Commission has contributed to updating the Vermont Department of Health's Action Plan on Alzheimer's and Healthy Aging. The plan will build off the first action plan created in 2018 and outline the objectives and strategies for our collective work on Alzheimer's and healthy aging. This project aligns with VDH's work under the BOLD grant.

The second year of the CDC BOLD grant, awarded to the Vermont Department of Health (VDH) in September 2020, is underway. Vermont's emergent Alzheimer's Disease and Healthy Aging Program hired a program manager and public health data analyst in Spring/ Summer of 2021. BOLD uses the Healthy Brain Initiative Road Map to augment our public health and primary care infrastructure, educate our communities and support caregivers. Since then, we have made strides enacting the BOLD objectives:

- Changing systems and environments to increase rates of early detection, risk reduction, caregiver support and reduction in avoidable hospitalizations related to co-morbidities, which become more difficult to manage when dementia is present.

Salient implementation steps achieved thus far include:

- Integration of brain health into chronic disease messaging on VDH's My Healthy Vermont platform and social and print media, along with creation of a monthly communication on brain health that highlights local efforts, current research and other relevant topics.
- Collaborating closely with the Department of Disabilities, Aging and Independent Living (DAIL) on promotion and implementation of interventions for primary care teams to expand their capacity to diagnose and manage Alzheimer's disease and related dementias.
- Revision and further development of the state Action Plan on Alzheimer's Disease and Healthy Aging is in progress. Diverse stakeholder input will broaden the impact of the plan and help make it an effective tool for public health and the broader community to address the needs of individuals with dementia and their caregivers.
- Collecting new brain health data pages are in process and will be published in early 2022.

For data requests or questions on any of the work outlined above, contact Ed DeMott, program manager [ed.demott@vermont.gov](mailto:ed.demott@vermont.gov)

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## Overview: The State of Alzheimer's and Dementia in Vermont



### VERMONT ALZHEIMER'S STATISTICS



#### PREVALENCE

**65+** NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S

Year	TOTAL	ESTIMATED % CHANGE
2020	13,000	<b>30.8%</b>
2025	17,000	



#### MORTALITY



DEMENTIA DEATHS DURING THE COVID-19 PANDEMIC

**47** more deaths than expected from dementia in 2020

**7.6** % higher than average

# OF DEATHS FROM ALZHEIMER'S DISEASE (2019)

**315**

5<sup>th</sup> leading cause of death



HOSPICE (2017)

**543**

# of people in hospice with a primary diagnosis of dementia

**17%**

% in hospice with a primary diagnosis of dementia



HOSPITALS (2018)

**1,528**

# of emergency department visits per 1,000 people with dementia

**19.6%**

dementia patient hospital readmission rate



MEDICAID

**\$ 116** MILLION

Medicaid costs of caring for people with Alzheimer's (2020)

**26.4%**

projected change in costs from 2020 to 2025



MEDICARE

**\$23,830**

per capita Medicare spending on people with dementia (in 2020 dollars)



CAREGIVING (2020)

**25,000** Number of Caregivers

**36,000,000** Total Hours of Unpaid Care

**\$717,000,000** Total Value of Unpaid Care

More than **6 million** Americans are living with Alzheimer's. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$355 billion** in 2021, increasing to more than **\$1.1 trillion** (in today's dollars) by mid-century. Dementia caregivers today are providing **20% more care** than in 2009.



For more information, view the **2021 Alzheimer's Disease Facts and Figures** report at [alz.org/facts](http://alz.org/facts). © 2021 Alzheimer's Association® All Rights Reserved. Alzheimer's Association is a not-for-profit 501(c)(3) organization.





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## Commission Membership 2021

NAME (alphabetical by last name)	REPRESENTATION
Mohamed Basha	Registered Nurses
Mark Boutwell	Area Agencies on Aging
Senator Randy Brock	State Senate
Susan Brooks	Business Community
Alecia Demario	Nursing Home Administrators
Molly Dugan	SASH Support Services at Home
Howard Goodrow	Alzheimer's Association
Glenn Jarrett	Legal Profession
Paula Johnson	Family Caregivers
Dr Alexandra Messerli	Physicians
Representative Dan Noyes	State Legislature
Janet Nunziata	UVM Center on Aging
Stephanie Parker	Residential Care
Roberta Rood	Mental Health Providers
Josh Smith	Social Workers
Pamela Smith	Clergy
Angela Smith-Dieng	Dept. of Disabilities, Aging, and Independent Living
Andrea Stauffenecker	Adult Day Providers
Deborah Wesley	Home Health Providers
Rhonda Williams	Vermont Department of Health

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2. [2020 State Unit on Aging Survey](https://asd.vermont.gov/sites/asd/files/documents/2020%20Needs%20Assessment%20of%20Vermonters%20Age%2060%2B%20And%20Their%20Family%20Caregivers.pdf) of of Older Vermonters (60+) and unpaid family caregivers for individuals 60+ <https://asd.vermont.gov/sites/asd/files/documents/2020%20Needs%20Assessment%20of%20Vermonters%20Age%2060%2B%20And%20Their%20Family%20Caregivers.pdf>
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