## Report to The Vermont Legislature

## Governor's Commission on Alzheimer's Disease and Related Disorders Annual Report 2024 and Professional Educational Opportunity Report (Appendix A)

Submitted to:	The House Committee on Human Services The Senate Committee on Health & Welfare
Submitted by:	<b>Dr. Jill Bowen, Commissioner</b> Department of Disabilities, Aging, and Independent Living (DAIL)
Prepared by:	The Governor's Commission on Alzheimer's Disease and Related Disorders

Report Date: January 15, 2025

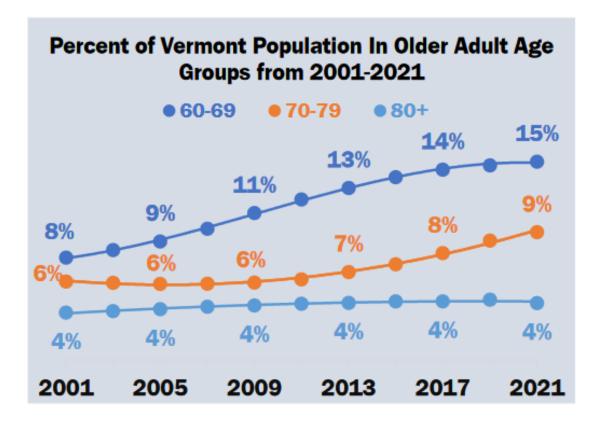


AGENCY OF HUMAN SERVICES

Alzheimer's disease and related dementias are on the rise in Vermont and around the world. It is projected there will be more than 17,000 Vermonters over the age of 65 living with dementia by 2025. The impact of living with and caring for those with dementia is costly for families, our state, and our nation. In 2022 the unpaid value of Vermonters caring for someone with dementia was \$590 million dollars.

One in four Vermont residents is over the age of 60 (28% or 183,000 adults). 2022 census data ranks Vermont as the 4th oldest population in the country. Since 2001, Vermont has experienced a decreasing youth and an increasing older adult population. The largest by decade age group is Vermonters between 60-69 years who now make up 15% of our population. The percentage of older adults living alone and experiencing cognitive decline increases with age.

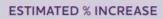
The Governor's Commission on Alzheimer's Disease and Related Dementias (ADRD) has worked closely and collaboratively this year to identify ways to support those living with dementia, understand the causes of and reduce the burden facing unpaid caregivers, educate primary care providers around dementia, and engage the general public in risk reduction. Through these collaborations and with the knowledge and experience of the ADRD, we have advanced some of the goals of our 2022-2025 State Plan on Alzheimer's Disease and Healthy Aging, passed impactful policy, and continued to raise awareness throughout the state.



# **VERMONT** 2023 ALZHEIMER'S STATISTICS

#### NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S

YEAR	TOTAL
2020	13,000
2025	17,000





## PREVALENCE



7,770 <sup>#C</sup>

# OF HOME HEALTH AND PERSONAL CARE AIDES IN 2020

32.7% INCREASE NEEDED TO MEET DEMAND IN 2030

## WORKFORCE



UNPAID CAREGIVERS (2022)	CAREGIVER HEALTH (2021)			
<b>19,000</b> # OF CAREGIVERS	61.5% OF CAREGIVERS WITH CHRONIC HEALTH CONDITIONS			
28,000,000 TOTAL HOURS OF UNPAID CARE	35.4% OF CAREGIVERS WITH DEPRESSION			
\$590,000,000 TOTAL VALUE OF UNPAID CARE	10.7% OF CAREGIVERS IN POOR PHYSICAL HEALTH			
CAREGIVING				
HOSPICE (2017)				
543 # OF PEOPLE IN HOSPICE WITH A PRIMARY DIAGNOSIS OF DEMENTIA 17% HOSPICE RESIDENTS 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				
\$116M MEDICAID COSTS OF CARING FOR PEOPLE WITH ALZHEIMER'S (2020) 2	26.4% PROJECTED CHANGE IN COSTS FROM 2020 TO 2025			
MEDICARE				
\$25,064 PER CAPITA MEDICARE SPENDING ON PEOPLE WITH DEMENTIA (IN 2022 DOLLARS)				
HEALTH CARE				
# OF DEATHS FROM ALZHEIMER'S DISEASE (2019)				
315				

## MORTALITY

More than **6** million Americans are living with Alzheimer's, and over **11.5** million provide their unpaid care. The cost of caring for those with Alzheimer's and other dementias is estimated to total **\$345** billion in 2023, increasing to nearly **\$1** trillion (in today's dollars) by mid-century.

For more information, view the **2023 Alzheimer's Disease Facts and Figures** report at **alz.org/facts.** © 2023 Alzheimer's Association® All Rights Reserved. Alzheimer's Association is a not-for-profit 501(c)(3) organization

## **ADRD 2024 Legislative Priorities**

In his opening remarks for the VT Age Strong Plan, Dr. Levine writes, "Older Vermonters are the fastest growing demographic in the state, and by 2030, one in three Vermonters will be 60 years or older." In 2025 there will be 17,000 Vermonters over the age of 65 living with Alzheimer's disease or another dementia. Despite additional allocations from the legislature and great effort from State Agencies and community partners, we remain without the capacity to adequately support Vermonters with dementia and their caregivers. This is primarily due to a severe workforce shortage, particularly of those who can help meet non-medical needs. The ADRD will support any efforts to grow this workforce sector. Without people to help care for Vermonters with dementia, the burden placed on family caregivers, residential care facilities, and hospitals will continue to grow. It is imperative that we do all we can to fund programs and ensure adequate reimbursement rates for those working in the Home and Community Based Service sector. We also need to increase support for unpaid family care partners, who are desperately trying to meet the needs of Vermonters with dementia.

## Priority #1: Double the Dementia Respite Grant to \$500k/year.

VT Age Strong Principles for Aging Well outline the importance of family caregivers and their needs. "Family caregivers are fundamental to supporting the health and well-being of older Vermonters, and their hard work and contributions should be respected, valued, and supported. Family caregivers of all ages should have affordable access to education, training, counseling, respite, and support that is both coordinated and efficient."

The Dementia Respite Grant, accessed through our five Area Agencies on Aging, provides flexible funds to help family caregivers safely keep their loved one at home. This grant is funded through General Funds and <u>has not been increased since 2003</u>. Increasing this allocation will help meet the needs of some of our most vulnerable Vermonters and will move us toward the VT Age Strong Valuing Family Care Partners Objective #1: By 2029, reduce the percentage of family care partners providing care/ assistance 40 hours or more in an average week to a friend/family member from 19% to 9%.

# Priority #2: Fully implement the increases for Enhanced Residential Care (ERC) and home-based choices for care contained in the DVHA rate study report from Feb. 15, 2023.

Severe workforce shortages and chronic underfunding that long predate the COVID-19 pandemic are jeopardizing Vermont's system of home and community based long-term care. ERC and home-based Choices for Care provide necessary care and services outside of nursing homes, allowing Vermonters to stay in their homes and communities longer as their needs change.

Our VT Age Strong plan identifies the value of keeping the long-term care system viable to provide older adults the care they need in the location of their choice. One proposed strategy would "Increase the investment for home- and community-based services to substantially reduce the number of Vermonters living in hospitals and nursing homes with no alternative."

#### Priority #3: Incorporate Dementia in Public Health Campaigns

Age Strong VT is built on "collaboration, integration, and expansion of health programs, aided by options for policy and greater funding for chronic disease prevention, that sets the stage for optimal health and wellness as an age-friendly state."

An Act relating to public health outreach programs regarding dementia risk would codify some of the important work that is underway within Alzheimer's and Healthy Aging and Chronic Disease Management at the Department of Health. This bill will require that brain health and dementia risk reduction be included in any existing, relevant public health or mental health outreach programs and will help us meet our goals of reducing the risk for chronic disease in Vermont.

## Priority #4: Include Vermonters with ADRD in planning and development of housing related efforts.

As housing will be a top priority this session, it is critical to make the needs of those living with dementia known and included. In addition to HCBS funding, we will advocate for embedded support services in existing and new housing communities, and expanding residential care capacity for individuals living with ADRD.

VT Age Strong urges identification of "opportunities to create affordable dementiafocused housing that meets universal design standards and incorporates the personcentered Best Friends<sup>™</sup> approach to memory loss to reduce the long waitlist for those with lower income looking for residential memory care."

## Priority #5: Restore \$2 million Moderate Needs Group (MNG) Funding and ensure it is available for all Vermonters with ADRD.

MNG is part of Choices for Care, which provides long-term care services and supports to older or physically disabled individuals. MNG funding allows many older Vermonters to remain in their homes and maintain their quality of life, providing access to services such as case management, homemaker services, and adult day services.

Last year \$2 million was cut from MNG funding due to underutilization, but the VT Extending HCBS Report (Nov. 15, 2023 draft) identified the great need for these funds and listed numerous ways to increase utilization. These funds are imperative in meeting the needs of Vermonters with ADRD and their caregivers.

The Commission will work with the legislature as it reviews the final VT Extending HCBS Report, to help convey the importance of these flexible funds and to ensure clinical eligibility crite-ria includes those with Younger Onset Alzheimer's and takes into consideration caregiv-er needs and capacity.

## 2023 Highlights

## **Legislative Successes**

The ADRD identified three areas for legislative focus in 2023. Through our collaborations with the Long Term Care Crisis Coalition, the Alzheimer's Association, the Community of Vermont Elders (COVE) and others legislation was passed to advance all three of these goals.

#### Building and strengthening the workforce including direct care workers

One of the greatest challenges to finding and retaining sufficient workforce and maintaining the continuum of programs that allow Vermonters to age in place has been reimbursement rates and pay. The ADRD Commission advocated for increases identified in a rate study report from the Department of Vermont Health Access (DVHA). The FY24 budget included a 79% increase in Assistive Community Care Services (ACCS) rates, a 4% increase for Home Health Personal Care, Homemaker and Respite services, and at 15% increase for Enhanced Residential Care (ERC.) These increases are vital and impactful, but we recognize they do not satisfy the full need as recommended in the Rate Study Report and much work is still needed to stabilize this system and ensure these services are sustainable.

#### Streamlining statewide coordination of ADRD programs and supports

The ADRD Commission and Alzheimer's advocates raised awareness about the impact of lack of coordination and the need for a Statewide Dementia Coordinator. The FY24 budget included \$150,000 directed at DAIL to create a permanent Statewide Dementia Coordinator. This position will play a central part in our efforts to streamline and coordinate services.

## Supporting Home and Community Based Services and advocating for protections so Vermonters who choose to can safely age in place

Adult day care is an essential piece of the survival kit for so many touched by dementia and was critically underfunded. The FY24 budget increased their reimbursement rate to \$25/hour.

#### **Commission Membership**

Our membership is diverse. We have 18 members representing nursing homes and residential care, home health/VNA, adult day health services, nurses, physicians, social workers, mental health providers, clergy, legal services, and family caregivers. We have representatives from the Agencies on Aging, the University of Vermont Center on Aging, the Alzheimer's Association, and Veterans Health Administration. Several state agencies are represented in our membership, including DAIL, Department of Health, and Vermont Blueprint for Health program. Our members hail from all over Vermont, including Chittenden County (8), Windsor County (3), and one each from the counties of Addison, Caledonia, Grand Isle, Lamoille, Orleans, Washington, and Windham.

#### **Composition of the Commission**

In January, ADRD Commission members agreed there would be value in bringing the voices of Vermonters with lived experience to our meetings. We invited four individuals to participate as full members in 2023:

Laura Brooks - Care partner for husband who has Younger Onset Alzheimer's

Luba Routsong - Care partner for husband who has Alzheimer's

Darryll Rudy - Vermonter living with Alzheimer's

Pamela Smith – Vermonter living with Younger Onset Alzheimer's

We also have a consistent group of actively participating community members at meetings and in working groups. The value of their participation is summed up by community volunteer Mindy Clawson of Burlington:

"As a former caregiver and current advocate for dementia caregivers, my years-long attendance at the Governor's Commission on Alzheimer's and Related Disorders has provided a wealth of opportunities.

It has given me a deeper understanding of the statewide network of professional dementia services, the challenges they face, and the opportunities available to advocates to participate more frequently in this network.

Perhaps more important, it has allowed me to meet and forge relationships with individuals in this community. Knowing who to call when I am looking for information (or funding) or have ideas to share has given me a broader footprint in which to operate. And this works both ways: it also allows professionals without direct experience in dementia caregiving to better understand the challenges that family caregivers face.

Caregiver participation in the Commission has set a precedent, normalizing nonprofessional involvement in professional organizations and creating opportunities for other advocates to participate in discussions in an arena where decisions are made.

Finally, it has supported grass-roots programming, especially in providing funding for community-generated organized activities that support people with dementia and their caregivers."

## **Commission Activities**

One of the statutory charges of the ADRD Commission is to represent this demographic as broadly as possible. Below are some activities that appointed commission members and Vermonters with lived ADRD Experience have contributed to this year.

## ADRD Hub and Spoke Workgroup on ADRD

The Hub and Spoke Alzheimer's Disease and Related Dementias Workgroup has met monthly to discuss priority projects that would increase screening and early diagnosis and improve support for care partners. One project applies the structured approach used by the UCLA Dementia Care Model to a UVMMC Memory Program pilot that will help identify and support patients through a set of risk measures. By seeing high-risk patients more frequently, crisis events can be averted. Directors Mary Val Palumbo and John Taylor are prepared to start as soon as staff are hired and accredited.

The workgroup also contributed to a Project ECHO on Dementia Diagnosis and Care with UVM Area Health Education Center (AHEC). Approximately 70 health professional staff enrolled, and the 5\five sessions have been well-attended.

The workgroup has brought on new members, including a retired physician, an Adult Day Center director, and an Office of Local Health Chronic Disease employee. Guests have included the Health System Director with the New England Alzheimer's Association to discuss new therapies and Project Independence's director to discuss the multiple ways an Adult Day contributes to physical, emotional, mental health of the attendee including those with dementia in addition to the care partner. Several workgroup members coordinated small group meetings including Dartmouth Neurology Memory Clinic and with the UCLA Dementia Care Model team.

Professional Data Analysts (PDA), the Alzheimer's and Healthy Aging Program evaluator is updating the data the workgroup is monitoring to assess if the state is gaining traction in early diagnosis and care over time.

## Age Strong VT

Age Strong VT is a new 10-year visionary plan with strategies for making Vermont a great place for all ages and stages of life.

The work on this unique multi-sector plan began with the passage of the Older Vermonters Act in 2020, and the Advisory Committee has been diligently working the last two years to listen to Vermonters, analyze current data and systems, and identify areas for growth and improvement.

Many of the commission's members, guests and advocates participated in the stakeholder engagement sessions and drafting of measures designed to support caregivers and individuals with dementia living independently in communities.

## VT BOLD Program

Building Our Largest Dementia (BOLD) infrastructure efforts, funded by the CDC and enacted by the VDH Alzheimer's Disease and Healthy Aging Program (VADHAP), focus on dementia awareness and risk reduction, increasing early detection and diagnosis rates, reducing avoidable hospitalizations among individuals living with dementia and supporting care partners. This work is being done with partners including the Alzheimer's Association, Vermont Chapter, on providing dementia-capable training to the public health workforce and with UVM Medical Center and its Memory Program on training the medical workforce.

In 2023, VADHAP launched a media campaign for the public and healthcare providers addressing hypertension prevention and management as a way to protect brain health and reduce dementia risk. Data from One Care VT on Medicare Annual Wellness Visit (AWV) use statewide prompted VADHAP to develop a media campaign to promote awareness of AWV to bolster earlier detection of ADRD. A gerontology practitioner will address the Hub and Spoke for ADRD Workgroup in late 2023 to assess change in use over the past year and discuss among the coalition members how to raise awareness and the practice of using AWV among primary care to continue to increase utilization of AWV statewide.

A VDH Spotlight Session, a monthly professional learning opportunity for public health staff and community-based organizations, examined long Covid, neurodiversity and dementia risk. In March 2023, the program released Alzheimer's and Related Dementia Surveillance in Vermont, the state's first data pages on this important public health priority, which includes data on subjective cognitive decline, prevalence of ADRD in VT, Emergency Department visits for people living with dementia, and ADRD-related hospitalizations. In December 2023, the program released a Caregiver Lived Experience Data Brief, compiling personal stories of caregivers across VT and Caregiving data garnered from the 2022 Behavior Risk Factor Surveillance System (BRFSS). The program also participated along with the UVMC Dementia Family Caregiver Center, in *Successful Public Health Approaches in Dementia Caregiving: Vermont - A Virtual Roundtable Series* coordinated by the Public Health Center of Excellence in Dementia Caregiving at the University of Minnesota.

Thanks to the VADHAP's efforts, a dementia indicator in Healthy Vermonters 2030 will assess readiness to talk to a healthcare provider about memory concerns. Only about half of Vermonters address this with their doctors; the program aims to help patients do this. The VDH Office of Health Equity Integration and VADHAP promoted an *Indigenous Historical and Intergenerational Trauma Training* to educate healthcare practitioners, community-based organizations, and the public health workforce about the impact of trauma on the lives of individuals from priority populations subject to historical and contemporary discrimination and oppression. This is particularly critical when working with individuals who suffered trauma in their early years and are now living with dementia – as recent memory fade memories of past traumas move to the fore.

The Alzheimer's Association, VT Chapter, AARP, COVE, SASH and VADHAP along with the Office of Local Health in Barre collaborated on multiple screenings of *Keys, Bags, Names Words* – a documentary film about hope and aging in dementia –including in Brattleboro, St. Johnsbury, Barre, Burlington and virtually. The program also worked with the Commission, Alzheimer's Disease and Healthy Aging Workgroup and Hub & Spoke for ADRD Workgroup to assess Y1 Progress on Action Plan for ADRD and Healthy Aging. VADHAP worked with HARK Media, a communications contractor to design and launch Vermont's Dementia Friendly Communities webpage – an interactive tool that will enable interested individuals and communities to take steps toward becoming more dementia and age-friendly.

Lastly, the VADHAP team have been a part of presentations to various audiences sharing dementia-related data and our efforts to date including to coalition workgroup meetings, the Burlington Council on Aging and the American Public Health Association Annual Conference in Atlanta.

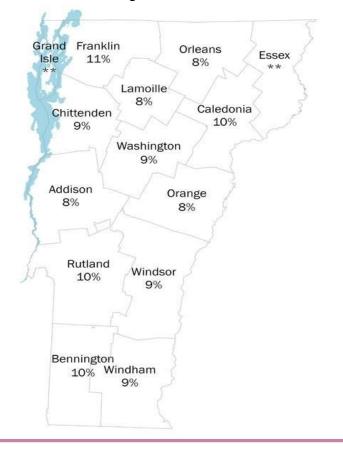
## **BRFSS Subjective Cognitive Decline and Caregiver Data Sets**

In March 2023, the first set of statistics focused on Alzheimer's and Related Dementia data was published on the Vermont Department of Health website.

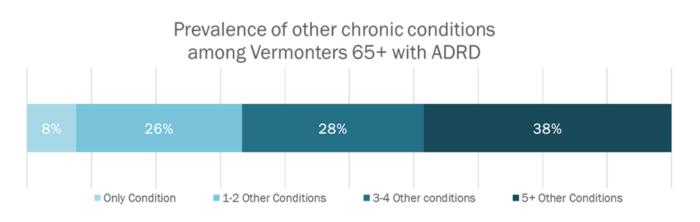
Some of the main findings include the following: In 2018: 9% of Vermonters 65+ on Medicare had an Alzheimer or related dementia diagnosis (ADRD), ranging from 8% in Lamoille County to 11% in Franklin County. Among Vermonters 65+ that were on Medicare and Medicaid, 22% had an ADRD diagnosis. Three percent of Vermonters younger than 65 years old and on Medicare had an ADRD diagnosis. Among Vermonters 65+ on Medicare, 10% of females and 8% of males had an ADRD diagnosis.

## Prevalence of Vermonters 65+

with ADRD by County

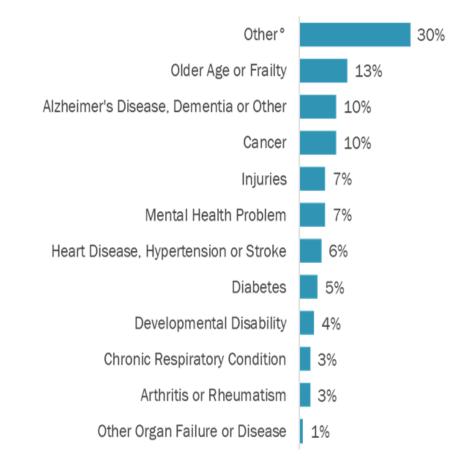


Approximately 38% of Vermonters with ADRD had five or more other chronic health conditions.

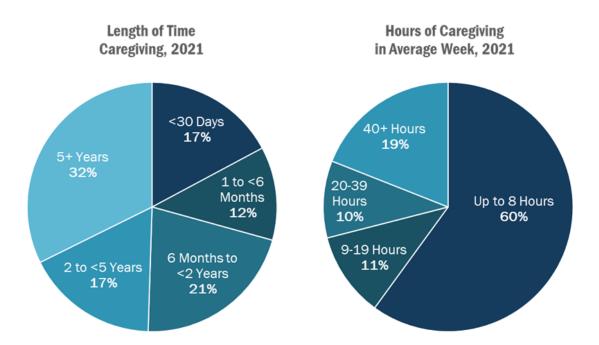


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## Main Health Problem, Long-Term Illness or Disability of Person Whom Caregivers Provide Care For, 2021



In February 2023, the Vermont BRFSS (Behavioral Risk Factor Surveillance System) Statewide Report was released for the year 2021. This contained information on the first time that the BRFSS caregiver module was asked. In 2021, 18% of Vermont adults reported providing regular care or assistance to a friend or family member with a health problem or disability in the past month. Women are statistically more likely to provide care than men. Nineteen percent of adults 65 years and older report being caregivers. In the next two years, one in seven Vermont adults expect to provide care or assistance to a friend or family member with a health problem or disability member with a health problem or disability (14%). Most caregivers report providing care for five or more years (32%).



In an average week, most Vermont caregivers (six in ten) report providing care or assistance for up to eight hours (60%). Eleven percent report providing care for nine to 19 hours, ten percent for 20 to 39 hours, and nineteen percent for 40 hours or more in an average week. In the past month, more than four in ten caregivers managed personal care such as giving medications, feeding, dressing or bathing (43%), and eight in ten caregivers managed household tasks such as cleaning, managing money or preparing meals (79%). Thirteen percent of caregivers report that they care for a person who also has Alzheimer's disease, dementia or some other cognitive impairment disorder.

## **DEI Workgroup**

The DEI committee, which is researching DEI policies and best practices, was reinvigorated this year. The committee will develop recommendations for service providers to use to provide a welcoming, safe and affirming work environment for professional caregivers and a competent and supportive care setting for adults living with ADRD.

The group is focused on a larger body of work to research and address the areas of interest that were identified:

1. <u>Training</u>: Ensure staff (even temporary/traveling) are trained in dementia basics, communication with someone experiencing cognitive decline, de-escalation

2. <u>Policy/procedure</u> development and implementation at executive/management level: What can be put in place to protect staff from abuse. Ensuring staff are informed of how to report and other procedures to expect when an incident occurs.

## **Dementia Friendly Vermont**

Our focus is to build public awareness and to support communities, such as Middlebury, that are launching their own Dementia Friendly initiatives. With support of the Commission, Middlebury has built a broad coalition of stakeholders who are working to make Middlebury "dementia friendly". The stakeholders include Isley Library, the town, individual businesses, Middlebury College students, and representatives of local older adult housing communities. A new Memory Café at the Isley Library will launch in January 2024 with support of the Dementia Friendly Middlebury Initiative.

Commission representatives and the Department of Health have created a Dementia Friendly VT webpage within the Department's Health Promotion and Disease Prevention content pages. Success of Dementia Friendly Vermont also requires establishing statewide Dementia Friendly practices to support individuals living with ADRD and their caregivers. The Middlebury initiative will serve as a role model for other communities that want to establish dementia friendly practices.

## **Geriatrics Conference**

This annual conference offers providers (MDs, APRNs, etc.) updates on caring for the older adult. Topics rotate regularly and focus on caring for older adults. In 2023, topics included: Age Friendly Care in Health Systems; Chronic Kidney Disease; Advance Directives; Innovative Strategies to Address Workforce Shortages. The 2024 Conference will be held on April 16, 2024.

## **Gerontology Symposium**

The UVM Center on Aging hosts an annual Gerontology Symposium that focuses on supporting those who care for persons living with dementia, including professionals and family (unpaid) caregivers. The conference attracts 100 to 200 participants from across Vermont. The goal is to provide current, research-based information on topics relevant to the broad range of health and service providers who work with our rapidly growing population of older adults. The conference attracts a broad audience, including social

workers, nurses, administrators, mental health professionals, and advocates for older adults, such as clergy. In the last few years, the symposium has also included family caregivers, who attend at a reduced registration fee. Exhibitors from community organizations, the Department of Aging and Independent Living (DAIL) and other groups help to keep the registration fees as low as possible.

Family caregivers and advocates for older adults appreciate learning about the collaborative work that's gaining momentum across Vermont as we seek to make Vermont the best state in which to grow older living with dementia. Conference topics from 2023 included: What can we learn from those living with dementia? Managing challenging behaviors as dementia progresses; Advocating for your care recipient and Fostering social inclusion and connection. The 2024 Conference will take place on May 7, 2024.

## Evaluation of Alzheimer's Disease and Related Dementias & Healthy Aging Plan

The Vermont Action Plan on Alzheimer's Disease, Related Dementias (ADRD) and Healthy Aging (2023 – 25) went into effect on October 1, 2022. It serves as a guide to improve the quality of life for all Vermonters by offering a framework for a multi-sectoral, collaborative response to ADRD through risk reduction, earlier detection, reduction of avoidable hospitalizations, and caregiver support. The Action Plan was developed by VDH's Alzheimer's Disease and Healthy Aging Program and its evaluation contractor with extensive input from stakeholder groups serving older Vermonters, particularly those living with ADRD and their caregivers. The Alzheimer's Disease and Healthy Aging Workgroup, the Hub & Spoke Workgroup on ADRD, and the Governor's Commission on ADRD examined the plan to determine the first year's progress. Group members were asked to provide examples of activities conducted in 2022-23 that supported the 5 Action Plan goals:

- 1. Improve healthcare quality to achieve greater health equity for Vermonters with dementia and their families.
- 2. Support all Vermonters with dementia, and their families.
- 3. Enhance public awareness and engagement.
- 4. Improve data to track progress.
- 5. Accelerate action to promote healthy aging and reduce risk factors for dementias.

Of the 114 strategies devised to meet these goals, 64 have begun or been completed in the first year of the 3-year plan. The full report on Action Plan progress for Year 1 is attached as an addendum to this 2023 Annual Report of the Governor's Commission on ADRD.

## **Professional Education Opportunity Report**

Act 113 of 2022 charged the Governor's Commission on Alzheimer's Disease and Related Disorders (ADRD) to create a Professional Educational Opportunities Report with *"recommendations to achieve a dementia-capable workforce and promote and expand opportunities for health care and human services providers and first responders to improve the* 

*diagnosis, treatment, and care of individuals with Alzheimer's disease and related disorders and to support their families and caregivers.*" This report will be submitted to the Senate Committee on Health and Welfare and to the House Committees on Health Care and on Human Services on or before January 15, 2024.

Over the last year we convened a working group, held three stakeholder meetings with representatives from different levels of residential care facilities and home and community-based service providers, interviewed individuals working with Vermonters with ADRD, talked with Vermonters living with and caring for those with dementia, and researched regional and national best practices.

In every conversation we heard the challenges the lack of workforce creates in caring for those with dementia. It is imperative we create stability in this system of care and adequate training will help to do this.

We identified three overarching themes we are recommending ensuring a dementia capable workforce in Vermont.

#### 1. Advantages of Universal Training -

It is important that those working with people with dementia receive similar training so, regardless of where they work, there are common skills, expectations, and approaches.

## 2. Everyone Needs Training -

In all sectors we heard strong advantages of all staff in an environment working with older Vermonters and people with dementia to have some training.

#### 3. Training Requires Resources -

Our meetings with stakeholders highlighted the benefits of training on staff retention and patient care. Lack of time was the main reason for reduced training.

In addition to training about how to diagnose, treat and care for people with dementia we identified a great need for training about what services are available in Vermont and how to access those services. This is imperative if we are to have a 'no wrong door' policy for access to support.

Our full Professional Education Opportunity report and recommendations can be found as Appendix A

## 2023 Governor's Commission on ADRD Membership

NAME (alphabetical by last name)	REPRESENTATION
Mohamed Basha, CEO TLC Homecare	Registered Nurses
Mark Boutwell, Executive Director Senior Solutions	Area Agencies on Aging
Randy Brock	State Senate
Neely Bryant, North Country Hospital	Social Workers
Alecia Demario, Executive Director Birchwood Terrace	Nursing Home Administrators
Molly Dugan, Director of Policy and Strategic Initiatives	SASH Support Services at Home
Jane Dwinell	Clergy
Kaili Kuiper, VT Legal Aid, Long Term Care Ombudsman	Legal Profession
Dan Noyes	State Legislature
Frederick Neu, Associate Director for Community Relations	UVM Center on Aging
Carolyn Taylor Olsen	Physicians
Mary Beth Pinard, Executive Director Vermont Catholic Charities	Residential Care
Meg Polyte, Policy Director	Alzheimer's Association
Sarah Poole, Dept of Veterans Affairs	Mental Health Provider
Simone Rueschemeyer	Family Caregivers
Angela Smith-Dieng, Adult Services Director	DAIL
Andrea Stauffenecker, Director, Riverside Life Enrichment Center	Adult Day Providers
Deborah Wesley, VP of Addison County Home Health & Hospice	Home Health Providers
Rhonda Williams, Chronic Disease Prevention Chief	Vermont Department of Health

## **Resources**

Age Strong VT https://www.healthvermont.gov/wellness/brain-health-dementia/age-strong-vermont-our-roadmapage-friendly-state

Alzheimer's and Related Dementias Surveillance in Vermont https://www.healthvermont.gov/sites/default/files/document/hpdp-brainhealth-data-report2023.pdf

Dementia Friendly Vermont https://www.healthvermont.gov/wellness/brain-health-dementia/what-are-dementia-friendlycommunities

## APPENDIX A

## **Professional Educational Opportunity Report**

Created by the Governor's Commission on Alzheimer's Disease and Related Disorders (ADRD)

January 15, 2024

## Introduction

Act 113 of 2022 charged the Governor's Commission on Alzheimer's Disease and Related Disorders (ADRD) to create a Professional Educational Opportunities Report with "*recommendations to achieve a dementia-capable workforce and promote and expand opportunities for health care and human services providers and first responders to improve the* 

diagnosis, treatment, and care of individuals with Alzheimer's disease and related disorders and to support their families and caregivers." Over the last year we convened a working group, held three stakeholder meetings, and have researched regional and national best practices.

As directed by Act 113, our work expanded beyond Long-Term Care facilities to the broader community of providers for those with dementia. We held three stakeholder meetings with participation from Home and Community Based Services (HCBS) providers, community volunteers, hospital administrators, SASH coordinators, the Area Agencies on Aging, Adult Day Program providers and Vermonters with dementia as well as family care partners. We found significant similarities in training needs across multiple sectors and settings. Through our meetings and research, we identified three overarching themes we must address to ensure a dementia capable workforce in

Vermont.

## 1. Advantages of Universal Training

- 2. Everyone Needs Training
- 3. Training Requires Resources

In addition to training about how to diagnose, treat and care for people with dementia we identified a great need for training across all sectors about what services are available in Vermont and how to access those services. This is imperative if we are to have a 'no wrong door' policy for access moreover 'to support'.

## **Vermont Statistics & Guiding Plan**

Data from the 2022 census now identifies Vermont as having the oldest population in the country. One in four Vermont residents is over the age of 60 (28% or 183,000 adults). We are projected to have 17,000 Vermonters over the age of 65 living with Alzheimer's and more than 20,000 unpaid dementia caregivers in the next year. Training will be required to meet the needs of this growing population and with an acute staffing shortage there are great benefits in identifying universal training programs.

## The 2022-2025 Vermont Action Plan for Alzheimer's Disease, Related Dementias & Healthy Aging identifies education and training as goal 1.

Goal 1: Improve healthcare quality to achieve greater health equity for Vermonters with dementia and their caregivers.

<u>Action 1</u> Strengthen the competencies of all who deliver healthcare and other care services through interprofessional training and other strategies to ensure trauma-informed, dementia-capable care.

<u>Action 2</u> Continue to assess and build a dementia-capable and culturally competent healthcare workforce to support people with dementia and their caregivers.

<u>Action 3</u> Education public health and human services professionals on sources of reliable information about brain health and ways to optimize services delivery for individuals with dementia.

This report builds on the efforts of the UVM Center on Aging, our Vermont Hub and Spoke Initiative for ADRD and other agencies and organizations who are educating providers by requiring evidence-based curricula be used for all people who are serving those with dementia.

## **Person-Centered Care**

Consistent in all our stakeholder meetings and validated through research is the value of personcentered care and the importance of adequate training to achieve this, regardless of setting.

"Person-centered care is a holistic and integrative approach designed to maintain well-being and quality of life for people with dementia" (NIH).

We heard many examples of the benefits of person-centered care, not only for the individual, but also as a way to build staff collaboration and improve retention, and to support the family care partner. We strongly recommend any training used be an evidence-based, person-centered model such as Best Friends or EssentiALZ.

## **ADRD Recommendations**

In November <u>2018 the ADRD sent a letter</u> to the Division of Licensing and Protection at DAIL outlining dementia care training recommendations for Long-Term Care facilities (Reference/link to letter.) The training themes identified remain the key themes and our recommendations for training across sectors today.

- 1. Understanding Dementia
- 2. Communication Strategies
  - 3. Person Centered Care
  - 4. Challenging Behaviors
- 5. Meaningful Activities and Social Engagement
  - 6. Role of the Environment

Currently, the Division of Licensing and Protection is in the final review stages with updates to requirements for residential care facilities. Included in the proposed update to regulations are enhanced training requirements, including some training for anyone working in the facility. The ADRD will continue to follow the update process and provide public comments to ensure the recommended updates align with our recommendations from 2018 and this report.

We recommend we expand required training on the topics listed above to all who work with people with dementia. This includes all employees of Home and Community Based Service organizations, Hospital employees with particular focus on emergency room staff, unpaid family care partners and care givers, and community volunteers.

We heard from numerous stakeholders the challenges of training staff while we are experiencing an acute workforce shortage and with a high level of staff turnover. We also heard how adequate training can reduce workplace stress and help with employee retention. What we know is Vermonters with dementia deserve to be treated with dignity and respect, regardless of where they are living, and this requires an understanding of the disease. We must ensure anyone serving those with dementia has at least a basic understanding of dementia, effective communication strategies, and dementia related behaviors.

Below are three recommendations to assist in building a dementia capable workforce in Vermont.

1. Establish Universal Training - It is important that those working with people with dementia receive similar training so, regardless of where they work, there are common skills, expectations, and approaches. This also ensures a person with dementia will receive similar care across settings. We recommend establishing a short list of Vermont approved training programs to meet training requirements. Training programs that are highly regarded and frequently used in Vermont include Best Friends, Teepa Snow and EssentiALZ. By having a list of recommend-

ed programs, organizations can save the time and burden of trying to create their own training program. We strongly recommend identifying how these educational opportunities can be made available to everyone, regardless of income, employer, or employment status. This includes unpaid family care partners and caregivers, community volunteers and any business that wants to make its sector more dementia friendly.

In our stakeholder groups we heard a lot about the advantages of having training linked to the person who receives it in addition to the organization they are employed by. This would allow staff more flexibility to move between organizations and would allow organizations a quicker onboarding process for staff who have recently been trained. This was identified as something that could help alleviate some workforce challenges.

- 2. Require Training for All Staff In all sectors we heard strong advantages of all staff in an environment working with older Vermonters and people with dementia to have some training. While the number of hours of training will vary depending on an individual's role, organizations that employed an all staff training model, such as being proposed for residential care facilities, shared many employee advantages and greater client outcomes. We recommend all staff in settings and organizations that serve older Vermonters receive some dementia training. For support staff and volunteers, such as custodians, cooks, or drivers, this would include understanding dementia, communicating with people with dementia, and working with dementia related behaviors. For administrative and leadership staff to fully support their team and to be able to fill in when staffing shortages occur, we recommend they receive the same training as someone working directly with a person with dementia. These recommendations would be required by all HCBS organizations, Senior Centers, Hospitals. As much as possible, training should also be provided to unpaid caregivers and people who volunteer for organizations serving older Vermonters and those with dementia.
- 3. Allocate Training Resources Our meetings with stakeholders highlighted the benefits of training on staff retention and patient care. Lack of time was the main reason for reduced training, but other barriers such as the cost of training, insufficient staff to cover shifts for those in training were also regularly mentioned. We recommend offsetting the burden of training. Several suggestions were raised in stakeholder groups including:
  - a. Purchasing training licenses or access at the state level
  - b. Providing resources to hire temp staff or cover additional hours to cover staff training time
  - c. Provide an incentive or bonus for organizations that reach an overall level of staff training
  - d. Having a central, easy to access location where training for unpaid family caregivers and direct care workers can access free training modules such as those offered through the Alzheimer's Association

There are likely other ways to support those serving this vulnerable population while they take time for training. What we heard very clearly was a lack of capacity to absorb additional requirements. Education is a priority so we must find ways to support organizations, facilities and staff to meet additional requirements.

## **Training of Medical Professionals**

Due to limited resources we were not able to identify or evaluate how medical professionals are taught about dementia as they pursue their degrees. We have a very active ADRD Hub & Spoke group in Vermont that actively works to provide medical professionals opportunities to learn about advances in diagnosis and treatment and the importance of early detection. This includes Project Echo for primary care teams and SASH Coordinators to learn about best clinical practices for Alzheimer's and other dementias, including practices related to screening, diagnosis, treatment, and referrals.

There are also VT Health Learn online modules specifically dedicated to dementia that are developed and maintained by the ADRD Hub & Spoke group.

This Commission, the Vermont Department of Health, the UVM Center on Aging and others are actively exploring and promoting opportunities to enhance understanding and ability to diagnose and support Vermonters with dementia and their family care partners in an effort to increase diagnosis at local practices.

## Training around "no wrong door"

Act 113 of 2022 amended our State Statute to create a central location for dementia related information. In order to realize a 'no wrong door' policy around dementia we must ensure these public education resources are created and easily accessible for all.

We recommend creating a short training on this resource, how to access it, and how to report programs and resources that should be added. Our stakeholder meetings highlighted numerous programs, community resources, and organizations serving those with dementia that were often unknown even to those working in the same region. A lack of clarity around resources available, how to access them, and requirements for utilization became abundantly clear. We heard a lot of frustration from our participants with lived experience who shared examples of misinformation and contradictory messages being given to them. We also heard from a wide variety of providers that they do not know where to look to understand what resources are available. The creation of this public education resource should be a high priority. We recommend creating a short training on the public education resources, how to access it, and how to report programs and resources that should be added. Our stakeholder meetings highlighted numerous programs, community resources, and organizations serving those with dementia that were often unknown even to those working in the same region. A lack of clarity around resources available, how to access them, and requirements for utilization became abundantly clear. We heard a lot of frustration from our participants with lived experience who shared examples of mis-information and contradictory messages being given to them. We also heard from a wide variety of providers that they do not know where to look to understand what resources are available. The creation of this public education resource should be a high priority.

33 V.S.A. § 6221 is amended to read:

#### § 6221. PUBLIC EDUCATION RESOURCES

(a) The Departments of Health and of Disabilities, Aging, and Independent Living shall jointly develop and maintain easily accessible electronic, print, and in-person public education materials and programs on Alzheimer's disease and related disorders that shall serve as a resource for patients, families, caregivers, and health care providers. The Departments shall include information about the State Plan on Aging as well as resources and programs for prevention, care, and support for individuals, families, and communities.