# Report to The Vermont Legislature

## Governor's Commission on Alzheimer's Disease and Related Disorders Annual Report 2024

**Submitted to:** The House Committee on Human Services

The Senate Committee on Health & Welfare

Submitted by: Dr. Jill Bowen, Commissioner

Department of Disabilities, Aging, and Independent Living

(DAIL)

Prepared by: The Governor's Commission on Alzheimer's

**Disease and Related Disorders** 

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Governor's Commission on Alzheimer's Disease and Related Disorders (ADRD) Annual Report to the Legislature, 2024

#### **Executive Summary**

Vermont's older population is our fastest growing age group. By 2030, one in three Vermonters will be over the age of 60 and while dementia isn't a normal part of growing older, aging is the #1 risk factor. There are over 13,000 Vermonters over the age of 65 diagnosed with Alzheimer's and many more with other forms of dementia or who are undiagnosed. We continue to hear about the increasing stress and burden on caregivers, who provided \$615 million dollars of unpaid care to Vermonters living with dementia in 2023. VT ALZ Fact Sheet The Commission is consistently advocating for expansion of infrastructure and programs to meet the needs of this growing population.

Our work, and the work of addressing ageism in our state, is bolstered by the work of Age Strong Vermont and our 10-year multi-sector plan for aging well. The Age Strong Plan recognizes and integrates the needs of Vermonters with dementia and their care partners in their goals and strategies and supports our work by decreasing stigma and highlighting the needs of Vermonters with ADRD for housing, transportation, social engagement, justice, healthcare and more. We strongly support and value the Age Strong plan and are active participants in implementation plans. We recognize the fragility of the long-term care system across settings and services and focus our work on ensuring stability and growth of this system. Lack of direct service workers, lagging and insufficient reimbursement rates, housing shortages and the rising cost of health care all impact the services and support Vermonters with ADRD and their caregivers receive. Additionally, challenges with access to and gaps in collecting data are a barrier to clearly identifying needs and tracking success with programs supporting the ADRD community.

Lived experience advocates start most Commission meetings with testimony to help us deepen our understanding of barriers and opportunities and help evaluate our work through the lens of real-world experience.

### **Programs and Progress**

In February 2024 the State Unit on Aging added the position of Dementia Services Coordinator (Approved by the Legislature in 2023). Through this position we have adopted an outline of the Dementia Service System from the National Institute of Health to organize where gaps and barriers exist. In the first six months of the position the Dementia Service Coordinator initiated 3 case studies across different geographic locations of the state to explore challenges accessing services and supports experienced by caregivers, and individual living independently with Alzheimer's Disease and a medical professional seeking home and community supports for an individual with early onset dementia. These case studies highlighted:

 Deficits in dementia capability at the HCBS and Health network level that reduced access to community supports.

- Ineffective communication between state agencies and caregivers when onboarding a loved one with dementia into a long-term care Medicaid program.
- Evidence that both clinical institutions and community organizations had challenges connecting individuals living independently with the support they needed during the early stages of dementia.
- Stress on families and the HCBS organizations due to lack of Adult Day programs and other opportunities for respite.

We will continue to follow these cases and other examples to improve and guide our work.

The Alzheimer's Disease and Healthy Aging Program at the Vermont Department of Health (VDH) continues to administer the BOLD grant with the mission to expand and improve the care for Alzheimer's Disease and Related Dementias (ADRD) in Vermont, guided by the VT Action Plan for ADRD & Healthy Aging 2022 – 2025. This approach is based on the CDC's Healthy Brain Initiative State and Local Road Map for Public Health 2023-2027. The goals of this 5-year cooperative agreement with the CDC, and in collaboration with the Governor's Commission for ADRD, Hub and Spoke for ADRD and the Chronic Disease and Brain Health Partnership, is to:

- 1. Grow our Vermont Dementia Coalition by focusing on geographic breadth and representation from priority populations.
- 2. Educate the general public, providers, clinicians and other professionals about ADRD topics.
- 3. Continue implementing the VT Action Plan and develop the second Action Plan 2026 -2029.
- 4. Increase the availability and use of data to improve knowledge, assess, plan and implement priorities.
- 5. Deepen community-clinical linkages among health care systems and existing services, public health agencies, and community-based organizations while increasing the public's awareness of them.
- 6. Improve the sustainability of ADRD efforts.

The Commission continues to engage with Vermont Department of Health's <u>BOLD</u> <u>program</u> and supports its efforts. In the past year, the VDH BOLD grant supported the development of two additional **Project ECHO Series**, created by the Hub and Spoke for ADRD: Dementia Diagnosis and Care for the Primary Care Team and Advanced Topics in Dementia Care for the Primary Care Team. The BOLD grant also partially funded the establishment of the **Vermont Alzheimer's and Dementia Care Project** at UVMMC Memory Program. This new project is based upon the evidence-based UCLA Dementia Care Program. UCLA coached us on best practices for hiring a dementia care specialist and a dementia care assistant, utilizing our EHR and billing codes, and

developing metrics to track our progress for evaluation purposes. The Project launched in March of 2024 and has already expanded with a satellite clinic at Elder Services, Inc. in Middlebury. To continue building a professional infrastructure that supports aging and older Vermonters, particularly those at risk for and diagnosed with dementia, the BOLD grant also contributes funds to the **VT-Bridges** Program Coordinator position. The VT-Bridges program helps bolster the Geriatric Social Work workforce in Vermont through recruitment, mentoring and career placement. The program is also convening leaders in Springfield to build the region's dementia capability, seeking to increase awareness, knowledge and use of Annual Wellness Visits (a Medicare benefit), Advance Directives and the Springfield Adult Day services that can benefit those with cognitive issues and their caregivers.

With the Vermont Alzheimer's Association and DAIL, the VDH Alzheimer's Disease and Healthy Aging Program organized Vermont's 1<sup>st</sup> Dementia & Brain Health Symposium. Over 80 people, including nurses, social workers, case managers, occupational therapists and other allied health professionals, registered for the symposium. The main themes of the symposium included ways to reduce dementia risk, advances in treatment and detection, improving access to care, and how to support caregivers for people with dementia.

Due to strong clinical evidence on the relationship between hypertension and brain health, the team is participating in the Hypertension Quality Improvement Learning Series. The VDH Chronic Disease Prevention Chief presented our work on chronic disease and dementia risk reduction and integrated communication strategies, including the relationship between brain health, diabetes, hypertension management, and smoking cessation.

In January 2024 the Commission submitted their 'Building a Dementia Capable Workforce' as required by <u>Act 113</u> of 2022. We used our recommendations to submit public comments to <u>Residential Care Home (RCH) and Assisted Living Residences (ALR) Licensing Regulations</u>. We were successful at expanding dementia education requirements from 'direct caregivers to all staff to interact regularly' The challenges that are still present are specificity to who receives this training.

During the 2024 legislative session lived experience advocates and members from the Commission testified in support of <u>S.302</u> which was passed as Act 164. This Act focuses on dementia education and awareness for both the healthcare workforce and the public. It requires dementia education, including the value of early diagnosis and ways to reduce the risk in all existing and relevant public health campaigns. In 2024 Vermont included the Cognitive decline module in their annual Behavioral Risk Factor Surveillance System (<u>BRFSS</u>) survey, We supported including the Caregiver Module in the next survey cycle. These are vital in creating a baseline of impact and need in Vermont.

The Commission advocated for and helped distribute data briefs created by the Vermont Department of Health to educate and raise awareness around caregiver challenges, Risk factors, and Subjective Cognitive decline.

#### Caregiving in Vermont Lived Experience Brief

Health Promotion Disease Prevention: State Aging Overview

Health Promotion Disease Prevention: Subjective Cognitive Decline

The Commission is helping grow and expand Dementia Friendly Middlebury (DFM) where the Isley Library and At Home Senior Care launched a Memory Café and provided opportunities for community education. DFM leads continue to engage all local sectors in discussion about creating a Dementia Friendly Community. In August, Middlebury and Commission members hosted Congresswoman Becca Balint for a tour of Project Independence and their Adult Day Program, conversations with local businesses, and a round table discussion with 17 participants focused on the needs and challenges of building a *Dementia Friendly* and *Dementia Capable* community. This fall an intern from Champlain College has been working to expand opportunities for communities to join this effort in and around Chittenden County.

The Commission has been following the development and expansion of UVM's approach to Dementia Care using an evidence-based model from UCLA. By establishing an <u>acuity classification system</u>, they are working towards a goal of reducing preventable hospitalizations in older adults with dementia.

One statewide program that has been struggling is <a href="TCARE">TCARE</a>, an evidence-based Caregiver assessment and referral program. This program was introduced via the 5 Area Agencies on Aging in 2021 but due to competency and capacity issues the program roll out was slow, and average caseloads and standards are not being met. This has made it difficult to use data collected in the program to ensure evidenced based outcomes and support advocacy efforts. For agencies that have been successful in program delivery, the data indicates interventions/referrals applied were helpful and the caregiver's stress and burden has not increased from their initial assessment. In 2024, TCARE specialists at the agencies worked to improve delivery of this service and build capacity by engaging in assessment pacing training, and receiving one-on-one consultation from TCARE technical assistance representatives to address challenges specific to their agency.

#### **2025 Policy Priorities**

The Commission monitors and supports policy proposals aligned with dementia risk reduction, quality of care for those with ADRD, and respite and well-being for unpaid caregivers. Additional priority legislation may be identified as bills are introduced. Current priorities include:

 Increase access to respite for family caregivers by raising awareness, increasing utilization and supporting stabilization funding for Adult Day Programs and advocating for an increase in the Dementia Respite Grant.

- 2. Improve access to diagnosis and treatment by supporting access to Biomarker testing.
- 3. Build sustainability in HCBS Long-Term Care system by advocating for full funding of increases for HCBS as described in the <u>2023 DVHA Rate Study</u>, inflationary adjustments in the FY26 budget, and for the establishment of an annual inflation factor to be applied to Medicaid reimbursement and HCBS providers.

#### Closing

The Governor's Commission on Alzheimer's Disease and Related Dementias maintains a diverse membership with geographic representation from across the state, many who are experts from organizations within the Aging Services Network. The membership of the Governor's Commission on ADRD is diverse. We have 18 members representing nursing homes and residential care, home health/VNA, adult day health services, nurses, physicians, social workers, and mental health providers, as well as clergy, legal services, and family caregivers. We have representation from the Agencies on Aging, the University of Vermont Center on Aging, the Vermont Chapter of the Alzheimer's Association, and Veterans Health Administration. Several state agencies are represented in our membership, including the Vermont Department of Aging and Independent Living, 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 member each from the counties of Addison, Caledonia, Grand Isle, Lamoille, Orleans, Washington, and Windham.

The commission also includes several lived experience advocates and other stakeholders across Vermont and bordering states. The Commission meets on the third Thursday every 2 months from 9-11am. To participate please contact <a href="mailto:Elizabeth.cronin@vermont.gov"><u>Elizabeth.cronin@vermont.gov</u></a>

NAME (alphabetical by last name)	REPRESENTATION
Mohamed Basha, CEO TLC Homecare	Registered Nurses
Mark Boutwell, Executive Director Senior Solutions	Area Agencies on Aging
Senator 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
Representative Dan Noyes	State Legislature
Frederick Neu, Associate Director for Community Relations	UVM Center on Aging
Carolyn Taylor Olson	Physicians
Mary Beth Pinard, Executive Director Vermont Catholic	Residential Care
Charities	

Meg Polyte, Policy Director	Alzheimer's Association
Sarah Poole, Dept of Veterans Affairs	Mental Health Provider
Simone Rueschemeyer, Executive Director of Vermont Care	Family Caregivers
Partners	
Angela Smith-Dieng, Adult Services Director	DAIL
Andrea Stauffenecker, Director, Riverside Life Enrichment	Adult Day Providers
Center	
Deborah Wesley, VP of Addison County Home Health &	Home Health Providers
Hospice	
Rhonda Williams, Chronic Disease Prevention Chief	Vermont Department of Health

Aging Services Network Partners
Ed Demott, BOLD Program Director
Tiffany Smith, VT Dementia Services Coordinator
Advocates Living with Alzheimer's Disease

Darryll Rudy
Pamela Smith

Advocates Caregiving for Someone Living with Alzheimer's Disease

Laura Brooks

Luba Routsong