

Hearing on Alzheimer's Disease and Dementia Care:

Current Services, Gaps, and Future Challenges

Vermont House Human Services Committee

Testimony

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February 12, 2015

Thank you for the opportunity to address this important issue.

PLANNING:

Three documents describe and guide state program and service planning for helping persons with Alzheimer's and other related disorders (ARD) and their families:

1. In 2009 DAIL, in conjunction with the Governor's Commission on Alzheimer's Disease and Related Disorders, produced the ***Vermont State Plan on Dementia***. This document provides a detailed portrait of the "Dementia System Landscape" along with seven recommended goals and fifty-six recommended activities. In the last 12 months the ARD Commission and partners have implemented 16 activities related to the three goals: 1) Increasing public understanding and awareness of ARD; 2) Increasing early detection of ARD; and 3) Increasing caregiver support
2. In 2013 DAIL commissioned the University of Massachusetts Medical School to produce a study entitled, ***Vermont Choices for Care: Alzheimer's Disease and Related Disorders***. This study assessed programs and resources for caring for individuals and families living with ARD and made recommendations specific to the Choices for Care (CFC) program and for addressing needs of Vermonters whether or not eligible for CFC. Key recommendations regarding improving dementia care outside of the CFC program include: a) Identify strategies to shift the care culture away from behavior management to person centered approaches; 2) Establish a statewide ARD training workgroup to disseminate best-practice person centered care; set standards for care with ARD staff; explore creation of annual statewide ARD Care conference; 3) Develop various types of public awareness vehicles about ARD and work with the BluePrint for Health to better identify and care for people with ARD.
3. A 2014 paper sponsored by the Administration for Community Living entitled ***Dementia-Capable States and Communities: the Basics*** articulates essential elements of state and community wide capacity for creating dementia-capable environment. Several of the seven elements are

covered in the State Plan and in the UMASS study including: 1) **Educate the public** about brain health—ADRD; 2) **Promote early detection** and timely resources to individuals and families; 3) **Promote person-centered care** that is family centered, self-directed and culturally appropriate; 4) Encourage the development of **dementia friendly communities**.

CURRENT DEMENTIA SYSTEM of CARE LANDSCAPE:

- **Choices for Care (CFC):** In 2005 the State implemented the Choices for Care (CFC) Program under an 1115 long-term care Medicaid waiver and has expanded Medicaid long-term care entitlement to pay for care and support for older Vermonters and people with physical disabilities beyond nursing homes. Supports include hands-on assistance with eating, bathing, toileting, dressing and transferring as well as assistance with tasks such as meal preparation, household chores and medication management. The overall goal of CFC is to give people choice and control over where and how their needs are met. For people who meet ‘nursing home level of care’ criteria, services are provided in their own homes, Adult Family Care homes, Residential Care/Assisted Living Homes, or nursing facilities. CFC offers a variety of self-directed options for people who live in their own homes who are able and willing to manage their own services, or who have a surrogate to manage services on their behalf. CFC provides limited funding for homemaker, adult day, case management, and “flexible fund” services to people in the “Moderate Needs Group.” The intent is to prevent or delay the need for more costly long-term services and supports by providing these services.
- **Older Americans Act (OAA):** The OAA provides funding for a range of programs that offer services and opportunities for older Vermonters to remain as independent as possible and to be active members of their communities. The OAA also provides a range of services for family caregivers to support them to continue this important role. The OAA focuses on improving the lives of older adults and family caregivers in areas of information and assistance, case management, housing, nutrition, health promotion and disease prevention, transportation, and other social and community services.
- **Long-term Care Facilities and Supports:**
 - **Residential Care Homes and Assisted Living Residences:** Vermont’s Residential Care Homes (RCH) are State-licensed Level III, Level IV and Level III/Assisted Living Residences (ALR). Although older Vermonters comprise the primary resident population, a sub-set of younger residents with disabilities are also served.
 - **Nursing Facilities:** Nursing homes provide nursing care and related services for people who need nursing, medical, rehabilitation and other special services.
- **Publicly Funded Home and Community-Based Care Providers:**
 - **Home Health Agencies:** Thirteen Home Health Agencies provide home care and related services in the home. Home care services include nursing, home health aide, homemaker, respite care, physical speech and occupational therapy, medical social services, hospice and other related services. People with dementia and their families collaborate in the development of comprehensive service plans that create the array of services and supports best for individual families.

- **Area Agencies on Aging (AAA):** Vermont's five AAAs provide support to people 60 and older in their efforts to remain active, healthy, financially secure and in control of their own lives. These agencies coordinate and support a wide range of home and community-based services including information, referral and assistance, case management, home delivered and community meals, health promotion activities, and family caregiver support services.
- **Adult Day Programs:** Fourteen Adult Day centers provide an array of services to help older adults and adults with disabilities to remain as independent as possible in their own homes. Adult day services are provided in community-based non-residential day centers creating a safe, supportive environment in which people can access both health and social services. Services include professional nursing services, personal care, therapeutic activities, meals, social opportunities, activities to foster independence as well as respite, support and education to families and caregivers.
- **Support and Services at Home (SASH):** SASH brings a care partnership together to support aging at home. The partnership connects the health and long-term care systems to 112 nonprofit affordable housing providers statewide offering a unique integration of housing, health, and long-term care supports. Local SASH teams, anchored by a housing based care coordinator (SASH Coordinator) and a wellness nurse, provide person-centered, evidence based care. **DAIL has supported the development of the SASH infrastructure including the expansion of SASH teams around the state; establishment of SASH coordination services at all SASH congregate housing sites; and the development of partnership MOUs.**
- **Home and Community-Based Support Programs:**

Two programs provide direct assistance to family caregivers of people with dementia. Long-term care needs are most often met by as combination of unpaid services provided by family members and paid assistance. More than three-quarters of community dwelling adults rely exclusively on unpaid long-term assistance from family members. The challenges and burdens of providing family care are well documented ranging from health impacts, job and financial, and mental stress.

 - **Dementia Respite Program:** The Dementia Respite Program is supported by State general funds and provides a limited amount of financial assistance to unpaid family caregivers of people with dementia. Program oversight and coordination is provided by DAIL and Vermont's five AAAs. To be eligible for a dementia respite grant, the care recipient must be a permanent resident of Vermont, have a physician's diagnosis of dementia, reside in a home setting and meet certain income eligibility requirements. Family dementia respite grants can be used to pay for services that provide family caregivers with a break from their caregiving responsibilities such as homemaker services (e.g. shopping, cleaning, and laundry), substitute in-home caregiving and adult day services. **DAIL provides \$250,000 annually to the Dementia Respite Program which in 2014 provided respite support to 282 families.**
 - **National Family Caregiver Support Program (NFCSP):** The NFCSP is an OAA program that provides an array of services and supports specifically designed for family

caregivers. Services include information about available services; assistance in gaining access to services; individual counseling; support groups and training to help caregivers make decisions and solve problems related to their caregiver roles; respite care to temporarily relieve caregivers from their caregiving responsibilities; and supplemental services on a limited basis to complement care provided by caregivers. **In FFY 14, 518 families were provided NFCSP assistance.**

- **Elder Mental Health:** The Elder Care Clinician Program serves adults age 60 and older experiencing mental health concerns such as depression, anxiety, substance abuse, and dementia. Program oversight is jointly provided by the Department of Mental Health and DAIL. Service delivery is coordinated by the AAAs and Vermont community mental health centers. Services are provided primarily in clients' home and include community outreach, mental screening, **dementia screening**, substance abuse and misuse screening, referral and supportive counseling.
- **Private Home Care Providers:** A number of private home care companies in the State provide non-medical care for a fee for individuals with dementia. The care is provided by caregivers and includes respite care, home maker services, companionship, transportation, meal preparation and assistance with personal care.
- **Development Disabilities Services:** A person with a developmental disability and dementia may be eligible for home and community based services which are coordinated through Vermont's community mental health centers. Home and community-based services are individualized and may include service coordination, home supports, respite, community supports, crisis services, clinical interventions and transportation.
- **Ageing and Disability Resource Connection (ADRC):** The ADRC is a "no wrong door" partnership supported by grants from the Administration for Community Living. Partners include the five AAAs, the Vermont Center for Independent Living, the Brain Injury Association of Vermont, Vermont 211, Vermont Family Network and Green Mountain Self-Advocates. The ADRC provides people with the information and support they need to make informed decisions about long-term services and supports. **Over 60 qualified Options Counselors work in the nine partner agencies.**
- **Homeshare:** DAIL supports two innovative Homeshare Programs in Vermont. **HomeShare Vermont is active in Addison, Chittenden, Franklin and Grand Isle Counties; HomeShareNOW is active in Washington, Orange and Caledonia Counties.** Homesharing arranges and supports live-in "matches" between Vermonters who have a living space to share and others who need a place to live and can offer support such as personal care, housekeeping, and socialization.
- **Vermont Alzheimer's Association:** The Vermont Alzheimer's Association offers a range of educational and supportive services for people with dementia, family caregivers, healthcare professionals and the general public. Services include a 24/7 telephone support line, statewide support groups, caregiver workshops, and training programs. The national Alzheimer's Association hosts and comprehensive website with detailed information helpful to people and families dealing with all stages of the dementia.

- **Specialized Memory Centers:** Specialized Memory Centers serving Vermonters are located in Burlington, Bennington, and Lebanon, NH. These Centers provide specialized assessment and diagnosis services and assistance in establishing plans of care.

GAPS AND FUTURE CHALLENGES: The planning documents at the beginning of this testimony provide a comprehensive analysis of the gaps and challenges for developing a dementia-capable state. The work to accomplish that status will take many years and will need to expand to meet the inevitable growth in the numbers of individuals affected by dementia. The first steps and priorities have been articulated by the Governor's Commission on Alzheimer's Disease and Related Disorders and include:

1. **Significantly improve public and leadership understanding** of Alzheimer's disease and related disorders
2. **Significantly improve early detection** of cognitive impairment and subsequent information and services people with dementia and their families
3. **Significantly increase services and supports for family caregivers** of persons with dementia

The Governor's Commission on ADRD has developed strategies to accomplish these goals. State resources need to be aligned to implement strategies to address these goals.