VERMONT STATE PLAN

on DEMENTIA



VERMONT

Agency of Human Services
Department of Disabilities, Aging & Independent Living

For More Information Contact:

Maria Mireault, M.A.

Dementia Program Director

(802) 241-3738

Maria.mireault@ahs.state.vt.us

Produced for the Department of Disabilities, Aging and Independent Living by:

Craig Stevens, MPH

JSI Research and Training Institute Inc.

cstevens@jsi.com

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ALDEN LAUNER

AMANDA MILLS-BROWN

BETH RIZZON

BILL PENDLEBURY, MD

CAMILLE GEORGE

CHRISTINA COSGROVE

CLIFFORD SINGER, MD

COMMISSIONER JOAN SENECAL

DAN BEAN

DEE ROLLINS

J. PAUL GIULIANI

JACKIE MAJOROS

JANICE CLEMMONS

JEFF MAKER

JEN HUNTER

KATHY HEMMENS

LAURA CORROW

LYNN BEDDELL

LYNNE IHLSTROM

MARCIA ELIOT

MARIA MIREAULT

MARLYCE WALLER

MARY ELLEN SPENCER

MARY SHRIVER

NANCY BOURNE

NANCY SCHAEDEL

PAM SMITH

PATRICE THABAULT

REP. PATSY FRENCH

SUE GOETCHIUS

VEDA LYON

SECTION I: INTRODUCTION

The prevalence of dementia is expected to increase significantly as the population of individuals over age 65 grows. In Vermont, where more than 20% of the population will be over the age of 65 by 2020, this is of particular concern. Dementia refers to a progressive decline in cognitive functioning due to damage or disease in the brain beyond what might be associated with normal aging. Alzheimer's disease is the most common cause of irreversible dementia and accounts for 50 to 70 percent of dementia cases. There are several other causes of dementia that account for the remaining 30 to 50 percent of cases.

Vermont continues to strive to meet the specialized needs of people with dementia and their families through innovative local and state programming. Through respite care programs, professional training, improving access to mental health programs and engaging specialty and primary care health professionals, we have improved the lives of many Vermonters. However, given the projected increase in the number of people age 65 and older, Vermont will not have the infrastructure necessary to support this growing segment of the population that is most likely to be affected by dementia illnesses.

The Vermont Department of Disabilities, Aging and Independent Living (DAIL), in its efforts to design and develop the State Plan on Dementia, convened a subcommittee of the Governor's Commission on Alzheimer's Disease and Related Disorders and other aging network providers. This subcommittee was charged with providing guidance and oversight for the development of a plan to help the state policy makers and stakeholders better understand how the estimated increase in people with dementia will need to be met with a corresponding increase in resources; including caregivers, specialized care units, respite services and education.

During 2007 and 2008, JSI Research and Training Institute Inc., under contract with the Department of Disabilities, Aging and Independent Living engaged in a planning process to develop a State Plan on Dementia. As part of this work JSI staff:

- **Project Task 1:** Conducted a literature search, secondary source review and inventory of state dementia activities.
- **Project Task 2**: Convened an advisory committee to oversee plan development.
- **Project Task 3**: Interviewed 20 community stakeholders.
- **Project Task 4**: Convened 4 focus groups with consumers or family members.
- **Project Task 5**: Convened 4 focus groups with aging services network staff.
- **Project Task 6**: Developed recommendations and prepared the final report.

Beyond the development of this Plan, the Department of Disabilities, Aging and Independent Living, in collaboration with the Governor's Commission on Alzheimer's Disease and Related Disorders, is raising awareness, convening partners and creating opportunities to improve the systems of care for people with all types of dementia and their family members. The State Plan on Dementia provides a framework for the ongoing efforts of DAIL and the Commission.

To find out more about the work of the Governor's Commission on Alzheimer's Disease and Related Disorders contact the Vermont Department of Disabilities, Aging and Independent Living at **http://dail.vermont.gov/** . An electronic copy of this report can be downloaded by visiting this website and navigating to the Publications and Reports section.

This report is organized into five sections and appendices. Immediately following this introductory section, the remaining sections are:

Section 2: Dementia System Landscape

Section 3: Summary: Focus Groups and Key Informant Interviews: Aging and Developmental Services Staff

Section 4: Summary: Focus Groups: Family Members and Non-Paid Caregivers

Section 5: Recommendations

Section 6: Next Steps

SECTION II: DEMENTIA SYSTEM LANDSCAPE

Overview of Alzheimer's Disease and Related Disorders in Vermont

Based on existing data sources, as well as findings from interviews with key Vermont stakeholders, this section provides a context for the current state of Alzheimer's disease and related disorders in Vermont. The information provided is limited by the lack of dementia-specific Vermont data. Future studies may benefit from well-documented baseline data from which to measure change.

A. Definitions and terms

Dementia refers to a clinical syndrome of significant intellectual decline or impairment that persists over time. To be classified as dementia, the syndrome must meet the following criteria:

a. "It must include decline in memory and in at least one of the following cognitive abilities:
   - Ability to generate coherent speech and understand spoken or written language.
   - Ability to recognize or identify objects, assuming intact sensory function.
   - Ability to execute motor activities, assuming intact sensory function and comprehension of the required task.
   - Ability to think abstractly, make sound judgments and plan and carry out complex tasks.

b. The decline in cognitive abilities must be severe enough to interfere with day-to-day life."[1]

Approximately 1% of dementia cases are caused by a physical or psychological condition that can be successfully treated, therefore a thorough medical history and physical examination is necessary to make an accurate diagnosis.

Alzheimer's disease accounts for 50 to 70 percent of cases nationally and is the most common form of irreversible dementia. In addition to Alzheimer's disease, other types of dementia include:

Vascular dementia

Dementia with Lewy bodies
Frontotemporal dementia
Dementia due to Parkinson's disease
Dementia due to Creutzfeldt-Jakob disease
Dementia due to normal pressure hydrocephalus

B. Demographics

The prevalence of dementia is expected to increase significantly as the population ages. In Vermont more than 20% of the population will be over the age of 65 by 2020. As such, Vermont will be impacted by aging-related diseases such as dementia.[2] The estimated increase in people with dementia will need to be met with a corresponding increase in

resources including caregivers, specialized dementia care units, respite services and education. Resources to assist families to plan for the future through estate planning and advance directives will also be needed.

There are more than five million people living with Alzheimer's disease or a related disorder in the United States. It is estimated that in Vermont, there are 11,000 individuals over age 65 with dementia. The prevalence of dementia in younger populations is also increasing, perhaps due to improved diagnostic ability. An estimated 500,000 Americans under the age of 65 have Alzheimer's disease or a related disorder.[1]

National research shows that Alzheimer's disease is more prevalent among African-Americans than among whites (with estimates ranging from 14% to almost 100% higher), but there are no Vermont-specific statistics on Alzheimer's disease by race. There is a greater familial risk and genetic and environmental factors may work differently to cause Alzheimer's disease in African-Americans.[3] A report by the national Alzheimer's Association also suggests that Hispanics may be at greater risk to develop dementia than other ethnic or racial groups. The burden of dementia is falling heavily on Hispanic/Latino families, particularly daughters and other female relatives, in part because of the strong sense of responsibility and the role of women in these communities but also because of the lack of culturally and linguistically appropriate and responsive health and community services. Given the growing racial and ethnic diversity of Vermont's population, it will be important to develop culturally responsive programs to serve these families.

Until recently, people with developmental disabilities often died at a fairly young age. Now, as a result of improved medical care and better living conditions, people with developmental disabilities are living longer and, like the general population of older adults, are at increased risk of developing dementia. The prevalence of Alzheimer's disease among adults with Down's syndrome is about 25% for those who are 40 years of age and older and about 65% for those who are 60 years of age and older. Due to their genetic makeup, people with Down's syndrome are especially vulnerable to developing Alzheimer's disease and onset of symptoms begins some 20 years earlier than in the general population. Among people with developmental disabilities other than Down's syndrome, the prevalence, age of onset and causes of dementia are similar to that of the general population. [4]

C. Screening, surveillance and epidemiology

Screening for cognitive impairment is the first step toward a diagnosis of dementia. While there are standardized cognitive screening tools, anecdotal information suggests older Vermonters are not routinely screened for cognitive impairment by their primary care practitioners.

The Vermont Department of Health, Health Surveillance Division regularly reports Alzheimer's-related mortality in their annual Vital Statistics Report. The 2005 report ranks Alzheimer's disease as the 7th leading cause of death in Vermont (Figure 1), similar to its

rank overall in the United States. While the number of deaths due to other causes have decreased in Vermont and overall in the U.S., documented cases of mortality due to Alzheimer's disease have increased (Figure 2). [5] Nonetheless, these data are believed to underestimate the actual number of deaths caused by Alzheimer's disease because this condition is underreported on death certificates. [6]

Figure 1: Leading Causes of Death – Vermont Residents, 1988 – 2003

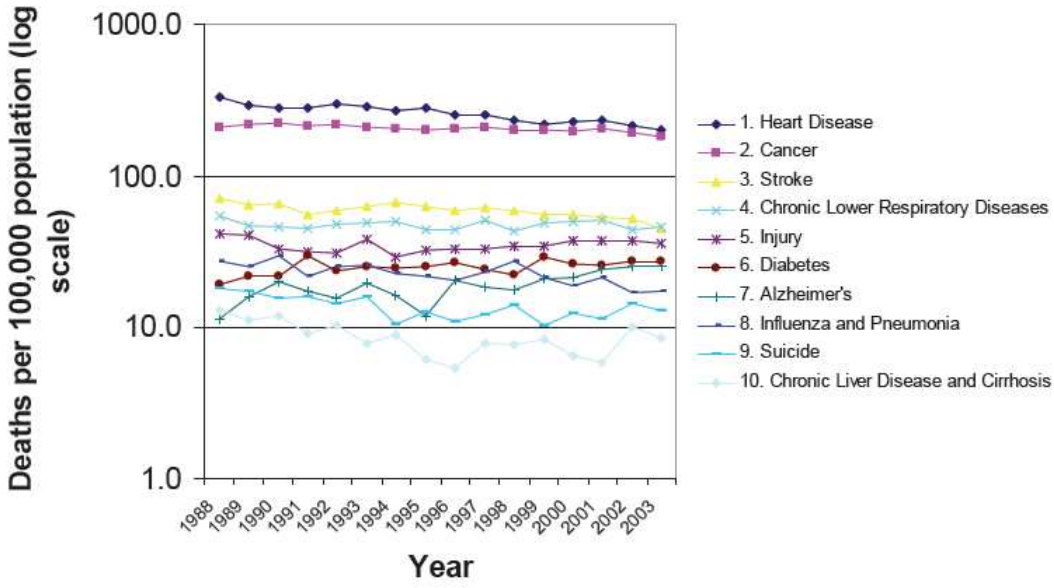


Figure 2: Leading Causes of Death (age-adjusted rates per 100,000 population) – Vermont and U.S. Residents, 2003 [5]

	Vermont		U.S.
	2003		2003
Heart Disease	199.6	↓	232.3
Cancer	181.8	↓	190.1
Stroke	45.2	↓	53.5
Chronic lower respiratory diseases	45.6		43.3
Injury	35.5		37.3
Diabetes	27.2	↓	25.3
Alzheimer's disease	25.3	↑	21.4
Influenza and pneumonia	17.2	↓	22.0
Suicide	12.9	↓	10.8
Chronic liver disease	8.5	↓	9.3

↓ = Rates have decreased over the past 8 years in Vermont
↑ = Rates have increased over the past 8 years in Vermont
Data Source: Vital Records, age-adjusted to the standard 2000 U.S. population

D. Cost of Care

Costs to provide care for people with dementia are substantially higher than health care costs for people with other chronic illnesses and threaten to take a heavy toll on long-term care resources.

Nationally, the direct cost to federal and state government and business was more than $148 billion in 2005. During that year, Medicare spent $91 billion on beneficiaries with dementia and those costs are projected to increase to $189 billion by 2015. State and federal Medicaid spending on nursing home care for people with dementia is expected to increase from $21 billion in 2005 to $27 billion by 2015. Costs to businesses with employees who are dementia caregivers are estimated at $36.5 billion as a result of decreased productivity, missed work and costs to replace workers who leave the work force due to caregiving demands.[6] Another source, *Koppel, R. Alzheimer's Disease: The Costs to U.S. Businesses in 2002,* shows the following total business costs for Alzheimer's disease in 2002 (in billions of dollars):

2002

For workers who are caregivers of people with Alzheimer's	$36.512
For health care for people with Alzheimer's	$24.634
Total business costs for Alzheimer's disease	$61.146

While Vermont-specific information regarding the costs of dementia is not available, more is known regarding the cost of care for individuals needing nursing home or home and community-based care. The average annual cost of a Medicaid beneficiary in a nursing home is $54,000 and the cost of home and community-based care is estimated at $28,000. Medicaid pays for approximately 68 percent of the long-term care nursing home beds in Vermont.[7] Many people with Alzheimer's disease and other dementias have co-existing chronic physical conditions and behavioral health needs and need long-term care services. Their healthcare costs are more than three times higher than those of people age 65 and older without dementia.[8]

Families and friends provide the majority of long-term care for people with dementia. During 2008 in Vermont, 15,848 caregivers provided more than 13.6 million hours of unpaid dementia care valued at $151,851,997. Family caregivers who leave the workforce to care for their loved ones at home lose income, health care and other benefits and employer contributions to their retirement savings. Those losses, combined with out-of-pocket expenses for the care recipients' personal care needs can have a significant impact on the caregivers' financial security. [8]

E. Dementia Care Infrastructure

Choices for Care

In 1996, in response to consumer demand for non-institutional options for long-term care and concerns about changing demographics and escalating public costs associated with facility-based long-term care, the State passed landmark legislation (Act 160) which enabled the government to gradually shift the balance in long-term care funding between facility-based and home and community-based services. 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, to include those who are seeking home and community-based services. 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 home based services can be provided either by a certified home health agency or though a consumer or surrogate-directed option. Under CFC, Vermont has implemented an option for spouses to be paid as caregivers, implemented Flexible Choices (a cash and counseling option providing individuals with flexibility in how they use their long-term care allocation to best meet their needs) and developed an Enhanced Residential Care program for residents of assisted living residences and residential care facilities who need more services than typically provided in these settings. Two PACE (Program for All-Inclusive Care for the Elderly) centers have also been opened. PACE is an integrated health care delivery system for nursing home eligible individuals, aged 55 years and older, that provides for all acute, primary care and long-term care needs of the individual. Care is provided or coordinated by an interdisciplinary team and services are financed through a combined Medicare and Medicaid rate.

The impact of Act 160 and CFC is clearly evident when comparing public expenditures for long-term care over the past decade. In 1996, before the implementation of the Act, an estimated 88% of long-term care expenditures were spent on nursing facility care compared to only 12% for home and community-based services.[9] By 2005, 68% of public expenditures for long-term care in Vermont were spent on nursing facility care compared to 32% for home and community-based services. Expenditures for the 2008 State Fiscal Year indicate that 58% of public expenditures for long-term care in Vermont were spent on nursing facility care compared to 42% for home and community-based services.[10]

Older Americans Act

The Older Americans Act (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 and contributing members of their communities. The OAA also provides a range of services for family caregivers to support them to continue this essential 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, employment, retirement, transportation and other social and community services. Older American Act funding is limited and cannot meet all needs of the growing population of older adults.

Long-term Care Insurance

Long-term care insurance is a product that, when appropriately purchased and used, can help people pay for part, if not all, of their long-term care needs. Most products now offered by insurance companies contain coverage for home care in addition to nursing facility care. The key is to purchase long-term care insurance earlier rather than later in life to keep premiums low. Consumers must determine their ability to continue to pay premiums. Recent changes in regulations now ensure that even if consumers are unable to continue to pay the premiums, they will still receive benefits up to the value of the premiums they were able to pay. Like reverse mortgages, long-term care insurance is a good solution for many people, but the pros and cons must be carefully weighed by each individual and adequate consumer protections must be in place.

The federal Deficit Reduction Act (DRA) offers a new option called *Long-Term Care Partnerships*. The goal of this option is to encourage consumers to purchase long-term care insurance by allowing them to use their full long-term care insurance benefit, still qualify for Medicaid coverage if they need it and retain more of their assets. An individual who has exhausted his/her long-term care insurance benefits may apply for Medicaid coverage and retain assets equivalent to the amount paid out for his/her care by the long-term care policy. Any long-term care insurance policy sold in Vermont must be approved by the Department of Banking, Insurance, Securities and Health Care Administration (BISHCA). The 2004 Legislature passed legislation that allowed Vermont to move forward with the partnership option as soon as federal legislation was passed (i.e., the Deficit Reduction Act). Vermont must now file a Medicaid State Plan Amendment with the Centers for Medicare and Medicaid Services (CMS), change the Vermont statute to bring it in line with the DRA and BISHCA must file the necessary rule changes.[11]

Caregiver Tax Credits

Taking care of a chronically ill person could qualify a caregiver for federal income tax deductions. Deductible expenses include personal care items such as disposable briefs and special foods; home improvements, such as grab bars; in-home care, such as physical or occupational therapy, nursing services, assisted living or other residential care and nursing home care.

Reverse mortgages

Reverse mortgages are a mechanism that might help some people use the equity they have built in their homes to help maintain their independence and, if necessary, pay

for long-term care expenses. This option is a solution for some people, but not for all. The individual receives payments from the lending institution, based on the equity in his/her home and the structure of the reverse mortgage they select. [11]

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.

Level IV RCHs offer a limited menu of service options, including room, board, some staff oversight and social supports. Level III RCHs and ALRs provide twenty-four/seven staffing, RN oversight, assistance with medications, three meals per day, housekeeping and laundry service and other social/supportive services. In addition, ALR residences must provide each resident with a private apartment that has a bath and kitchen, resident control of their unit (i.e. a lockable door) and the opportunity to 'age in place' within the ALR.

Individuals who need a residential environment due to chronic conditions, physical limitations, a diagnosis of dementia, or other conditions that require supportive services have a variety of choices available due to the great diversity within Vermont's residential care home provider network. In addition, a large number of RCHs and ALRs are state-approved Enhanced Residential Care providers who have the capacity to provide services that meet the needs of individuals who require nursing home level of care.

Daily rates at RCHs and ALRs are usually considerably less than those in a nursing home setting. In May 2009 the Division of Licensing and Protection licensed 103 Level III RCHs and 7 Level IV RCHs.

Nursing Facility Occupancy and Utilization

Nursing homes provide nursing care and related services for people who need nursing, medical, rehabilitation, or other special services. They are licensed by the State and may be certified to participate in the Medicaid and/or Medicare programs. Certain nursing homes may also meet specific standards for sub-acute care or dementia care.

As of May 2009 there were 42 nursing facilities in Vermont.[12] While many people live in nursing facilities, there are also many who receive nursing facility services for shorter stays for rehabilitative services, respite and palliative care. In 2005, the leading reasons for admission to a Vermont nursing facility were to receive short-term rehabilitation or skilled care (64%) and/or care needs related to a significant change in functional status (27%). [9]

Between October 2005, when Choices for Care was launched, and June 2009 there was a 10.8% decrease in the number of people who received long-term care in a nursing home and a 31.8% increase in the number of people eligible for nursing home care who chose to receive their long-term care through home and community-based services.[13]

Publicly Funded Home and Community-Based Care Providers

Home Health Agencies

Vermont's 13 Home Health Agencies (HHA) 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 are involved in service planning which includes a comprehensive plan of treatment and rehabilitation made in collaboration with the person's physician.

Area Agencies on Aging

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 (I/R & A), case management, home-delivered and community meals, health promotion activities, transportation, employment services, family caregiver support services and the long-term care ombudsman program. They also provide assistance for adults in need of protection or supportive services.

Adult Day Centers

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. There are 16 adult day centers located across Vermont (operated by 14 certified providers) as well as two PACE centers located in Colchester and Rutland which provide an expanded adult day program to manage participants' health, medical and social service needs.

Home and Community-Based Support Programs

Caregiver Support Programs

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. 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, laundry), substitute in-home caregiving or adult day services.

The National Family Caregiver Support Program (NFCSP) is an OAA program that provides an array of services and supports specifically designed for family caregivers. Family caregivers have long been described as the "backbone of long-term care" with nearly two thirds of older people with long-term care needs relying exclusively on family and friends. The National Family Caregiver Support Program is coordinated through DAIL and Vermont's AAAs to meet the unique needs of 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 relating 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.

Elder Mental Health

The Elder Care Clinician Program serves adults age 60 or older experiencing mental health concerns such as depression, anxiety, substance abuse or dementia. Program oversight is jointly provided by the Department of Mental Health and DAIL. Service delivery is coordinated by the AAAs and Vermont's community mental health centers. Mental health counseling and supportive services are provided by elder mental health specialists in clients' homes or in an office setting, depending on individual needs. Services include community outreach, mental health screening, clinical assessment, supportive counseling and medication monitoring.

Private Home Care Providers

There are a number of private home care companies in the State that provide non - medical care for a fee, for individuals with dementia. The care is provided by caregivers, in most cases the caregivers are supervised and a care plan is followed. The services are available 7 days a week, 24 hours a day. Services include respite care, home maker services, companionship, transportation, meal preparation and assistance with personal care. The private home care companies work in conjunction with the families and home health agencies to provide a full spectrum of care. The services are generally private pay and are not reimbursed by medical insurance, Medicaid or Medicare. The services can be provided in the home, assisted living facilities, nursing homes, or hospitals.

Developmental 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, employment services, crisis services, clinical interventions and transportation. In particular, home supports provide supports and supervision to people in and around their residences. Minimally, this may include hourly support in the person own home or that of a family member, or 24 hour support in a shared living home (with a contracted home provider) or a staffed or group living arrangement.

Nursing Home Diversion

The Nursing Home Diversion Project (NHDP) is a pilot project operated jointly by DAIL and two AAAs; the Council on Aging for Southeastern Vermont and the Central Vermont Council on Aging. NHDP services are available in Windham, Windsor, Washington, Orange and Lamoille counties. The project's primary goals are to provide individualized services to 200 individuals during the eighteen month project in an effort to divert older people from nursing home admissions. Program participants must be 60 years of age or older, at high risk for nursing home admission due to medical needs, chronic conditions, or need for personal/home care and ineligible for long-term care Medicaid. It is expected that one-third of NHDP enrollees will have a diagnosis of Alzheimer's disease or a related dementia. Participants' family caregivers are also eligible for services.

Aging and Disability Resource Connection (ADRC)

The Vermont Aging and Disability Resource Connection (ADRC) Project is funded by a grant from the AoA and the Centers for Medicare and Medicaid Services (CMS). The goal of the project is to assist Vermont in establishing virtual Aging and Disability Resource Connections that build upon existing agencies' capacities to deliver quality and comprehensive information, referral and assistance services (I/R & A). The Northeastern Vermont Area Agency on Aging, Champlain Valley Area Agency on Aging, HowardCenter and Vermont 2-1-1 are playing a lead role in the Vermont initiative. People of any age, ability or income will be able to turn to the ADRCs, as a seamless point of entry to programs and benefits, for information on a full range of long-term care options.

Housing and Supportive Services (HASS)

Service coordination and increased access to services are provided at certain congregate housing sites serving older adults and people with disabilities to enhance residents' quality of life and improve their ability to age in place. Resident service coordinators maintain a supportive presence on site and collaborate with a variety of community partners to increase access to homemaker services and provide health, wellness, education and socialization activities for residents.

Homesharing

HomeShare Vermont assists older adults and people with disabilities to live independently in their own homes by bringing them together with people who seek affordable housing and/or caregiving opportunities. Homemaking, meal preparation, home maintenance and other services are provided in consideration of reduced or free rent. HomeShare Vermont provides homeshare matching and caregiver matching services and is available in Chittenden, Addison and Grand Isle Counties. HomeShare of Central Vermont is a program of Central Vermont Council on Aging and offers homeshare matching services in Washington, Lamoille and Orange counties.

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 telephone information helpline, statewide support groups, caregiver workshops and training programs. The Alzheimer's Association sponsors an annual educational conference for family and professional caregivers, maintains a resource library of materials for those wanting more information about dementia and facilitates enrollment in the nationwide Safe Return program and other programs such as Care Trak Northeast for those at risk of wandering and getting lost. The Vermont Alzheimer's Association works in cooperation with the national Alzheimer's Association and other advocacy organizations to address key problems facing people with dementia and their families in Vermont.

Specialized Memory Centers

Specialized Memory Centers serving Vermonters are located in Burlington, Bennington and Lebanon, NH. These Centers provide specialized care for people with dementia and their families and are often integral to obtaining a diagnosis of dementia and establishing plans of care. Scope and type of services may differ at each location.

Long-term Care Capacity

Looking ahead over the next decade, it is expected that additional home and community-based programs and services will be needed to provide consumers with long-term care in the setting of their choice. In a recent study on long-term care sustainability, DAIL determined an average 2015 Projected Service Use Rate for the State, applied that rate to eight programs of interest and then determined the use rate for those programs for each county. Personal care under the Choices for Care waiver, adult day services, enhanced residential care, attendant services, homemaker services, assistive community care services (ACCS)*, assisted living residences and private pay residential care capacity were included in the forecast. Using this approach, in order to achieve the vision of a more balanced long-term care system in Vermont within the next ten years, all counties would need to increase their home and community based long-term care services, some more

*Assistive Community Care Service is a Medicaid State Plan service.

dramatically than others. Many home and community-based providers reported that current reimbursement rates make it difficult to meet the current needs and that, absent higher rates, expanding services would be very challenging. [11]

Long-term Care Workforce

While dementia-specific healthcare workforce data are unavailable, the 2007 Vermont long-term care sustainability study indicates that Vermont is undergoing healthcare workforce shortages with high turnover in the low paying, high hands-on care sector. [11] Even with increased efforts to recruit and retain health care professionals, it is expected that workforce shortages will continue and potentially worsen as Vermont's population ages. It is reasonable to expect that the shortages and turnover rates for the general healthcare workforce are also true for those caring for people with dementia.

Personal care attendants and licensed nurses' aides who work in long-term care facilities and home and community-based settings are in short supply. The problem is exacerbated by increasing demand for the services, low wages and poor or non-existent benefits. Staff shortages and insufficient time to provide quality care creates additional barriers to retaining workers to provide these important services. Although home and community- based programs such as Choices for Care give people the option to recruit, hire, train and retain their own direct care workers through consumer and surrogate-directed care options, there continues to be a shortage of available and well trained home care providers. Expanding this sector of the healthcare workforce is critical to supporting long-term care in home and community-based settings. There is an increasing need for providers who can offer nighttime and/or weekend respite care and an apparent shortage of caregivers to provide this type of assistance. The importance of supporting and encouraging family caregivers, including the need to provide them with information on hiring and managing paid caregivers, is noted by advocates and family caregivers themselves. [9]

F. State Research and Professional Training Activities

- The Center on Aging at the University of Vermont was established in 2008 through and an endowment from Lois McClure and funding from DAIL. The focus of the Center will be on research, professional training, policy and public education.
- Research on the use of melatonin to treat sleep disturbances in Alzheimer's disease has been conducted at the University of Vermont. Frequent nocturnal awakening is a common behavioral symptom of Alzheimer's disease. Nighttime wandering and agitated behavior may result in injuries for the person with dementia and sleep disruption for caregivers. Alternatives are needed to the currently available sleep medications that have marginal efficacy and serious side effects. Melatonin enhances sleep in older people in the general population and may reduce sleep disturbances associated with Alzheimer's disease.

- Researchers from the University of Vermont are examining the efficacy and safety of using nicotine patches to treat mild cognitive impairment. Nicotine could provide a way to treat the earliest signs of memory loss and attention deficits in people developing dementia. It will not stop the disease, but it may provide a way to delay the onset of symptoms.
- Scientists at the University of Vermont have clarified the cellular process responsible for signaling regional blood flow changes in the brain, thereby uncovering possible causes for such disorders as stroke, migraine and Alzheimer's disease.

G. State Health Planning

The Vermont Department of Health developed a State Health Plan in 2005. While no dementia-specific information was developed, the defined outcomes and activities have great relevance to the needs of people with dementia and their families and may serve as the basis for future collaborative planning between state entities responsible for public health and aging services. Similarly, the Vermont State Plan on Aging provides demographic information related to the aging population and outlines DAIL's goals for the future of aging services, including programs for individuals with dementia and their family caregivers. [9]

H. Public Education and Outreach

Community of Vermont Elders (COVE)

The Community of Vermont Elders (COVE) believes that informed and effective public policy is essential to achieve its mission of promoting and protecting a higher quality of life for Vermont's older adults. COVE's role is to work with older adults and the individuals and organizations that serve them to identify and research both problems and opportunities; develop proposals and strategies; inform and educate the public and policy makers; advocate for or against the adoption or revision of specific laws, rules, regulations or policies; contribute to the process of implementing policies and programs; and, monitor the effectiveness of policies and programs in achieving outcomes and objectives and advancing a higher quality of life. COVE is committed to ensuring that the needs, concerns, safety and wellbeing of older adults who are economically disadvantaged, physically or mentally challenged, or geographically or socially isolated are a central focus in the development and implementation of public policy.

SECTION III: SUMMARY: FOCUS GROUPS AND KEY INFORMANT INTERVIEWS: AGING AND DEVELOPMENTAL SERVICES STAFF

Three focus groups and twenty key informant interviews with staff working in an aging service organization and one focus group of staff working in a developmental services organization were conducted as part of the planning process. Several thematic areas emerged through these discussions, giving important insight into the highest priority issues and concerns of professionals working with people with dementia and their families. Below is a summary of the findings by thematic area.

Public Information

According to participants, there have been many positive changes in terms of public and professional understanding of dementia. "…for example, there has been an enormous awakening about family caregivers – just five years ago we were just beginning to think about them, we didn't even use that term." Still, efforts are needed to increase public awareness about dementia and change the belief that cognitive decline is an expected part of the aging process. More should be done to encourage individuals with cognitive impairment to obtain cognitive screening and see their primary care practitioners for thorough medical evaluation and accurate diagnosis. Greater public awareness about dementia can help break down the isolation experienced by individuals and families affected by dementia.

Participants stated it was important to raise awareness about the types of local resources available to individuals in the early stages of dementia, their families, caregivers and health care professionals. Many case managers indicated that they were the only avenue for families to access information regarding area resources and that this information should be more easily available.

Quality Improvement

Most of the discussions regarding quality improvement focused upon creating a system of care which was "dementia-informed". These discussions were different from those related to the dementia care infrastructure and underscored the difference between service inadequacy (because services were not available) and the inadequacy of existing services to be well equipped and meet the needs of people with dementia and their families (dementia informed). One exception to this statement is the view of primary care professionals and their role in the ongoing care of people with dementia. It was felt that primary care practices both needed to increase the level of services provided as well as the extent to which their services were dementia-informed.

Given that there are many services and potential interventions which can help people with dementia and their families, stakeholders felt strongly that primary care practices could play a very significant role in the identification of dementia through routine

cognitive screening. It was felt that routine cognitive screening is not completed by primary care physicians for several reasons including providers' lack of familiarity with cognitive screening tools, a lack of awareness of the benefits of early intervention and a concern regarding the lack of local services to help individuals diagnosed with dementia.

Involving Communities, Families and Consumers

A strong consumer voice in advocacy and with policy makers was felt to be missing in Vermont. While there was an understanding that some pockets of the state had individuals who were excellent advocates, an organized approach to ensuring consumers' voices are part of the ongoing dialogue is needed. Case managers and other aging service professionals often stated that there was a strong partnership between themselves and either people with dementia or their family members, but that on a policy level, there were inadequate numbers of engaged consumers or consumer families to represent the needs of this population.

It was mentioned that this partnership was difficult to develop because of the overwhelming and at the same time competing demands placed on caregivers and family members. Given that service providers felt that the role of caregivers and family members was daunting, they indicated that significant resources would have to be put in place in order to cultivate more meaningful participation and teamwork at the programmatic and policy level. The professionals participating in the focus groups and interviews underscored the power of the consumer voice – indicating the dramatic differences between when consumer voices are present and then noticeably absent.

Dementia Care Infrastructure

There was relative consensus regarding the lack of adequate services, particularly in rural, remote areas of Vermont. Aging network professionals indicated that there were problems with both the breadth of services available to support a continuum of care for people with dementia and their families, as well as a depth of services, indicating that services which did exist in their region lacked capacity to meet the needs of this population. Given that many of the individuals participating in focus groups were case managers, they felt that they had particularly good insight regarding the needs of the target population and their knowledge of available resources. In some instances, services (both community-based social services as well as conventional medical care) were available in some regions of Vermont but this posed problems in terms of travel, cost or interfered with family caregivers' schedules (most importantly work). The lack of adequate public transportation for individuals and families, the need for affordable senior housing with dementia-informed staff and the need to increase capacity of the adult day system were also identified as shortcomings of the existing dementia care infrastructure.

Dementia Care Workforce

While significant work has been done to understand the shortfalls of the current

healthcare workforce, no specific studies have focused upon the dementia care workforce. General consensus among key informants and focus group participants is that the healthcare workforce issues for the general population also apply to people with dementia. The demand for greater availability of skilled professionals who can provide quality care in all regions of Vermont is exacerbated by the unique needs of people with dementia.

Research and Policy

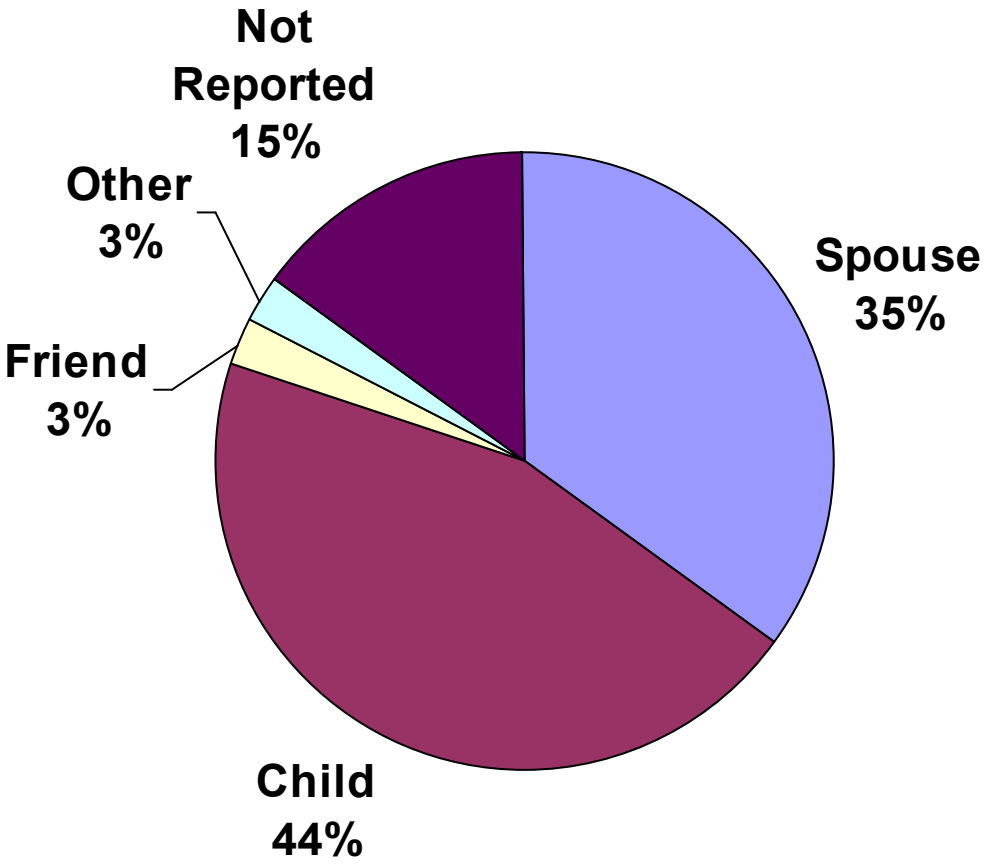
Many of the individuals who participated in focus groups and interviews expressed a frustration at their own lack of understanding of how to best provide care for people with dementia and their families. In particular, they were concerned that there was inadequate work being done around Vermont that would help inform policy decisions regarding how to organize and pay for care as well as promote evidence-based practices for people with dementia and their families. While less emphasis was put on scientific research, participants found it encouraging that Vermont's small population and rural environment has attracted some researchers to the state.

Given the newly established Center on Aging at the University of Vermont, people were very interested in the role that the University could play in improving the applied as well as basic research that could inform policy and quality of care.

SECTION IV: SUMMARY: FOCUS GROUPS: FAMILY MEMBERS AND NON-PAID CAREGIVERS

A total of four focus groups with family members and non-paid caregivers were held with a total of 37 participants in attendance. Individuals were provided a meal and a $25 stipend to attend. Twenty seven percent of attendees were male, 73% female with an average age of 65 years. Almost half were children of a person with dementia (see chart below). The remainder of this section describes the themes which cut across the focus group discussions.

Relationship of Focus Group Participant to Person with Dementia



Public Information

The concept of public education campaigns to increase awareness and decrease isolation was discussed in all of the focus groups. Focus group participants spoke openly about the feelings of isolation due to the intensiveness of caring for a family member alone. This feeling was described as being compounded by the ignorance encountered in physician practices and the community at large. Many focus group participants spoke of an "ill- prepared medical establishment" spanning the continuum from private practices to long-term care facilities in terms of knowledge deficits in caring for people with dementia. Several focus group participants found themselves in the role of educator-at-large as they interfaced with providers. This was exemplified by one focus group participant who stated, "The doctors do not understand. I've had to say to them that there is something wrong." Others spoke of the need to become independent learners, gleaning all that they could from a variety of sources including support groups, friends, the internet and the public library. Lastly, in support of more public information, participants commented that public education would also address the feeling of isolation experienced by people with dementia, helping them to realize and understand that they are not alone.

Quality Improvement

Training opportunities for health care professionals and community service providers was paramount in the discussion of quality of services. Building on the theme of an ill-prepared workforce in terms of knowledge and understanding of dementia, participants believed that there is room for improvement in the provider community, particularly in remote and rural areas of Vermont. Participants who had contact with more specialized care such as a memory center were highly satisfied with the services received. Focus group participants expressed strong support for a state-wide registry of skilled and credentialed dementia care providers such as the one that is currently under development by DAIL.

Involving Communities, Families and Consumers

Many focus group participants felt the extent to which communities, families and consumers are involved in dementia care is driven by the availability and accessibility of resources. Resources in terms of time and money direct the ability to access care, to involve family members who may be far away and to become an informed consumer. Other variables that influence involvement include geography (rural versus urban) and consumer awareness of dementia-related issues (because of lack of involvement in advocacy or education activities). Focus group participants described situations where their resourcefulness resulted in involving their communities in the care of a family member. One participant spoke of exploring a "home trade" option and found an individual interested in sharing a home in exchange for the provision of respite care. Efforts to engage community members and coordinate care require caregivers' time and energy, both which are in limited supply. One participant stated, "When I think about the information piece, the

most frustrating part was hearing 'Well, you could do this or that…'. There were always pieces I could do but never enough time to do them. There are so many tasks to do to access services, but never enough time." Another individual commented, "It is like running a company twenty-four/seven."

Dementia Care Infrastructure

Focus group participants explained that there are multiple portals to dementia-related support services. The majority of participants spoke of the randomness of their search to find these portals. Many stated that they found out about services simply by talking to people "on the way to the post office" or "at the supermarket." This informal network of information was frequently cited as the main source of information. One focus group participant stated, "You know someone who gets services and they alert you to something," whereas another participant stated, "Families are left to figure it out on their own," and lastly, "Ask everyone you know; you make a lot of phone calls, make a lot of contacts and ask for a lot of help." What resonated across focus groups was the desire for a system that triages cases while providing timely information so families are not left to guess about available services.

Cost of services was also stressed as a predominant issue, contributing to the issue of overall access. Services that are partially covered or not covered through insurance policies or state grants presented imposing barriers to the focus group participants. Many spoke of the time commitment necessary to blindly navigate the channels of payment and reimbursement systems, rarely with any certainty of knowing the appropriate point of entry into a system. Others spoke of the economic impact on themselves as caregivers after leaving a full time job to take care of a loved one. One focus group participant commented, "The economic impact is horrendous. It interferes with everything—taking away from employment to take care of a family member and doctor's expenses. There is the financial strain and the emotional strain."

If the issue of cost was mitigated, at least temporarily, the second access issue is the availability of services. In general, focus group participants were well informed of the services available to them, however, obtaining these services has been their biggest challenge. The types of services families utilize include transportation, respite care, specialized medical care, mental health counseling, social work, adult day, homemaker services and home-delivered meals. Each service is equally valued; however, the quantity and frequency of each service is often insufficient. For example, one focus group participant spoke of accessing services from a mental health counselor who was available intermittently at best. Focus group participants expressed frustration about the irregularity of services and commented on how this disrupts continuity of care for individuals who needed consistency, familiarity and routine.

Dementia Care Workforce

Focus group participants commented on the wide array of services utilized, including personal care attendants, home delivered meals and transportation services. The message consistently and repeatedly communicated was the need for dementia-specific education for providers to increase their understanding of the disease process and its relation to caregiving for people with dementia. The broad array of Vermont's community service providers were identified as a group who would benefit from further dementia-specific education and public awareness campaigns.

Policy Changes

The policy issue that rose to the top of the focus group discussions was the issue of payment mechanisms. Payment mechanisms including the provision of health insurance for family caregivers who left their jobs, the ability to access specialty care, stipends that cover employment loss in order to care for family members, prescription medication payment, payment for respite care and expanded payment/reimbursement to cover registered nursing services. Participants expressed the need for any and all policy changes that would support the payment for dementia care services.

SECTION V: RECOMMENDATIONS

A. Public Information

According to family caregivers, dementia care professionals and other stakeholders, general misunderstandings regarding dementia and the dementia care system continue to persist in Vermont. The most fundamental messages have not been incorporated into public dialogue regarding dementia:

- Dementia is not a normal process of aging.
- Early detection of cognitive decline and early intervention can help families, caregivers and people with dementia in significant ways.
- Our current systems of care are ill-prepared to manage the increasing prevalence of dementia.

Given these issues, public information campaigns may be an important element in creating a ground swell of awareness; dispelling myths, mobilizing individuals and communities into action and changing the current paradigm regarding dementia.

In Vermont there is great potential to expand the dissemination of information and use of public education campaigns regarding dementia. Significant consideration should be given to campaigns and communication methods which use broad-based, consistent messages and an array of media approaches. In addition, alternative methods should build the capacity of prominent individuals, community leaders and organizations so that they too can communicate strategic messages to the public, press and peers. It will be important to recognize the importance of relationship building in the success of both a broad-based, grassroots campaign and the type of participatory communication approaches which resonate with specific segments of the public. For example, the approaches for employers, young adults, spouses or partners and children of people with dementia should be tailored to obtain the greatest impact and effect.

Goal: Vermonters are adequately informed regarding dementia.

Objectives should include activities which create messages to increase awareness, change attitudes which perpetuate the idea that dementia is a natural and acceptable course of the aging process, increase help-seeking behavior, recognition and improve self management. Messages should be targeted to specific populations (e.g., spouses, family members, medical community and employers).

Objective: Design a broad-based dementia and brain health public information campaign.

1. Activity: Develop and implement traditional widespread communication campaigns including public service announcements, dissemination of literature, bus placards,

resource centers at libraries and other appropriate placement of information and messages. These efforts can be integrated into existing initiatives including the Aging and Disability Resource Connections.

Objective: Design a grass roots information dissemination campaign.

1. Activity: Integrate brain health messages into other health improvement efforts in the community settings frequented by older adults (e.g., senior centers, community meals programs and other wellness programs).

2. Activity: Include grass roots dissemination of messages, particularly those which build capacity within the community. For example:

- Replicating programs which use lay people trained as health promoters and information disseminators in the community, most often key respected community members who are seen as reliable sources of information.
- Convening local summits for the public or for people with, or affected by dementia. The AARP Brain Health Ambassador Program may serve as a model.
- Engaging naturally occurring outreach organizations such as faith-based communities and senior centers and training their staff.
- Engaging high schools and colleges that require community service projects as part of their requirements for matriculation or graduation.
- Utilizing the Community of Vermont Elders senior expressive arts programs to incorporate messages into their performances, or visual arts programs dedicated to older artists, such as the GRACE project.
- Partnering with local Vermont Department of Health offices and community health centers that share a common focus of information dissemination and community wellness.

B. Quality Improvement

Institute of Medicine (IOM) Definition of Quality:

"The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."

The Institute of Medicine (IOM) has been engaged in an initiative focused upon assessing and improving the quality of care in the United States. Since that initiative began in 1996, the IOM has produced numerous reports on the status of quality in our health care system and the particular barriers to improving quality of care. As a result of this

work, we have begun to more thoroughly understand the pervasiveness of the problems related to quality in our health care system and the health care industry has gained a better understanding of the disparities in health care, the absence of evidence-based and standardized practices and the lack of person-centered approaches and continuity of care.

While over a decade of work has transpired since the first IOM report, it is widely understood that there is still a vast gap between the current status of quality and quality initiatives and where we would envision our ideal health care system. This sentiment was reflected by both providers and consumers through the development of this Plan and spanned the broad scope of services supporting people with dementia and their families. From specialty care to home and community-based supportive services there is a concern that we are not able to provide services in a manner which is based upon the best evidence and customized to meet consumer needs and values. Nor do we have a system that promotes cooperation among clinicians and the consumer that allows the person to be the source of control or anticipates the person's needs rather than simply reacting to events.

Goal: A strong quality improvement system exists to support the ongoing enhancement of dementia care.

Objective: Establish a dementia quality initiative to direct efforts to measure and improve dementia care across health care settings, including home and community-based care and promote person and family centered services.

1. Activity: Integrate quality improvement activities for dementia with other chronic disease initiatives such as the Vermont Blueprint for Health.

2. Activity: Promote the use of best practices in nursing homes, residential care and assisted living residences, adult day centers and home health services. Examples of best practices may include those developed by the national Alzheimer's Association as part of their Campaign for Quality Residential Care.

http://www.alz.org/professionals_and_researchers_quality_care_initiative.asp

3. Activity: Provide training and orientation to consumers and family members of individuals newly diagnosed with dementia regarding the condition, the system of dementia care and social supports.

4. Activity: Monitor the impact and effectiveness of new initiatives such as the application and effectiveness of new legislation on guardianship.

5. Activity: Provide training and technical assistance to primary care practitioners and other professionals (eye, dental, hearing, mental health) to facilitate adoption of dementia screening, treatment and management in their practices. Training and technical assistance should focus on assisting the practice in integrating dementia-informed activities into the practice system of care.

6. Activity: Document and disseminate best practices regarding advanced models of dementia care in primary care, palliative care, hospice and other end of life care services.

7. Activity: Develop staffing resources for a dementia quality initiative in collaboration with the Vermont Program for Quality in Health Care.

8. Activity: Develop measurable criteria for defining dementia-informed systems of care. These definitions may be tailored for a variety of care providers, for example: primary care practitioners, nursing homes, residential care homes, adult day centers and HHAs.

9. Activity: Design and standardize care management plans which are outcome focused. Central to this activity will be a priority to develop strength-based care management approaches to address both the clinical and social needs of people with dementia. These plans may be tailored for a variety of care providers including primary care practitioners, nursing homes, residential care homes, adult day centers and HHAs.

10. Activity: Provide training and technical assistance to health care professionals to support use of standardized care management plans.

11. Activity: Define and disseminate existing knowledge regarding evaluation of nursing home culture change that reflects a dementia-informed long-term care setting.

12. Activity: Promote small demonstration or pilot projects regarding nursing facility culture change. Such projects should demonstrate ability to meet expected outcomes of culture change.

13. Activity: Initiate programs which promote cognitively stimulating services in homes, nursing homes, residential care homes, assisted living residences and adult day centers.

C. Involving Communities, Families and Consumers

"Advocacy is about taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support. Advocacy promotes social inclusion, equality and social justice." (Action for Advocacy)

Involving communities, families and caregivers can be viewed through the concepts of empowerment and advocacy. Empowerment and advocacy are increasingly important tools in engaging people with dementia and their families. New research demonstrates the links between empowerment, advocacy and improved quality of life. With the increasing population of Vermonters over 65 and the parallel increases in the prevalence of dementia, strong consideration should be given to including this population in designing, evaluating and directing how their needs can best be met. Given the potential for early detection of dementia, engaging people frequently, as well as early in the disease process, is entirely feasible. With the expected increase in the number of people with dementia, we can

anticipate an increase in the number of families and friends acting as caregivers, who similarly should have a voice in the design of a dementia-informed system of care.

Goal: Vermonters are active stakeholders in the system of dementia care.

Objective: Establish initiatives which promote a sense of responsibility and provide the necessary resources to support active involvement in advocacy, care and self management.

1. Activity: Develop dementia volunteer programs that engage a diverse group of stakeholders including family members, faith-based institutions, high schools and colleges, the Alzheimer's Association, the Retired Seniors Volunteer Program (RSVP) and other natural partners to increase awareness and understanding of dementia and to expand supports to people with dementia and their families.

2. Activity: Develop state policies regarding benefits and subsidies to family caregivers, which promote active involvement of families in dementia care. These incentives can be in the form of monetary incentives, tax incentives, health care coverage or deferred income incentives (retirement) as well as non-monetary incentives such as eligibility to obtain counseling and support for family caregivers through Choices for Care and other state or locally sponsored programs.

3. Activity: Develop state policies regarding subsidies for adult day services, similar to those for child care settings, which support, enable and supplement active caregiving by families and friends.

4. Activity: Establish and support consumer and family involvement in public advocacy through advocacy training and financial supports such as travel reimbursement and funding for respite care.

5. Activity: Engage policy makers in ongoing discussions with consumers and families regarding state policies and regulations.

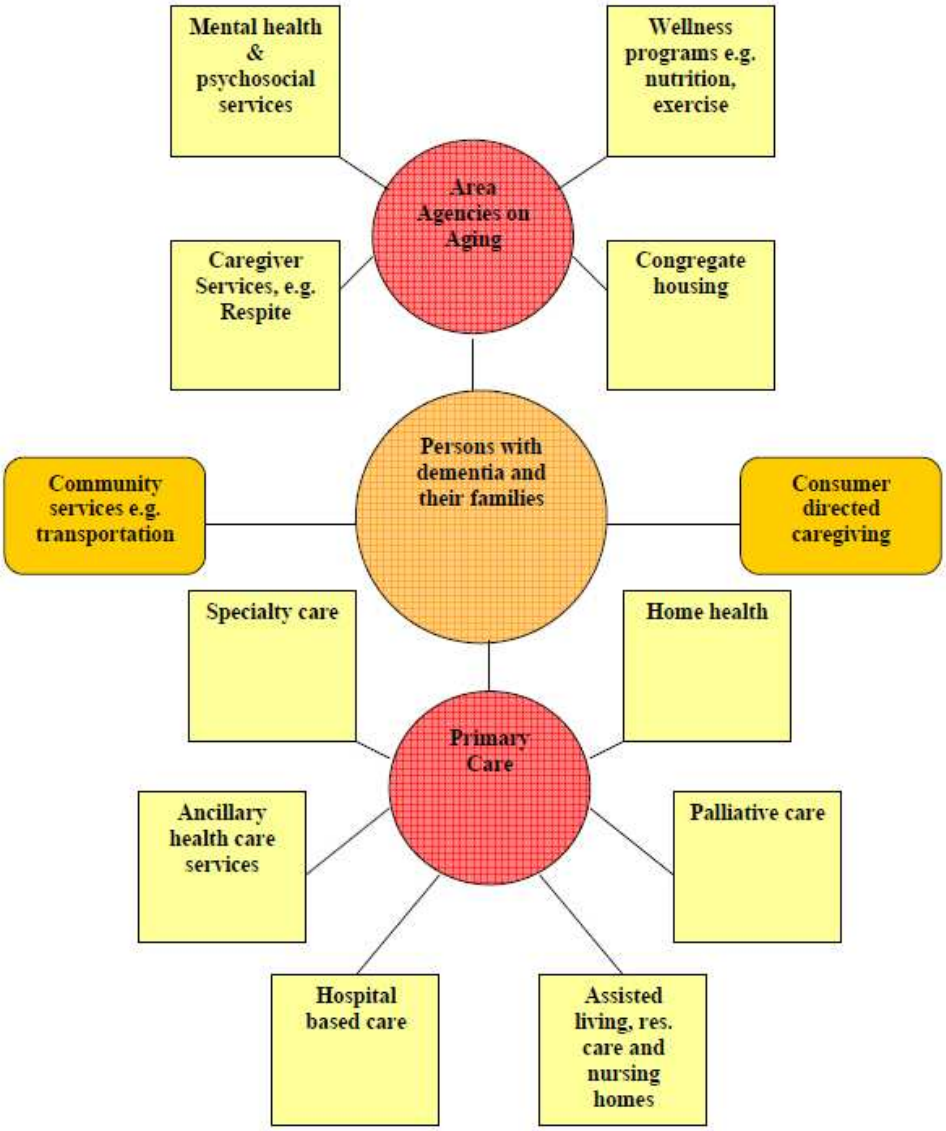
6. Activity: Establish a broad network of partners in the areas of business, education and manufacturing to promote brain health and wellness programs and help educate the public on the importance of early detection of dementia, available resources for people with dementia and caregiver support.

7. Activity: Promote programs which:

- Ensure home safety through falls prevention programs, home safety assessment, and home monitoring devices.
- Help people with dementia and their families prepare for care and services in the event of a disaster or emergency.

- Ensure safety in the community such as the Care Trak program and the Alzheimer's Association Safe Return Program and promote legislation that would support search and rescue of missing people with cognitive impairment.
- Develop employer-supported dementia caregiver training and other employer supported programs.

D. Dementia Care Infrastructure



People with dementia and their families are eager for solutions to develop a coordinated and more easily accessible system of care in Vermont, particularly in the more rural, remote areas. In an environment of unlimited resources, it would be ideal to have access to the spectrum of home and community-based supportive services, acute care, specialty care and long-term care in the communities in which people live. Given that the resources to develop such a comprehensive spectrum of care are not available, Vermont needs to explore efficient integrated approaches to the provision of dementia care. According to the Vermont Behavioral Risk Factor Surveillance Survey (2007) over 85% of Vermonters have a primary care practitioner and over 65% have seen a doctor for a routine physical exam within the past year. Primary care practitioners reach a very large segment of the general population which providers in other settings can rarely achieve. Given this level of contact, development of more efficient and effective integrated systems of care in Vermont's rural, remote areas that include primary care as a major stakeholder and coordinator of care may very well provide a model approach to the provision of services in a dementia-informed system.

Goal: All Vermonters with dementia have equitable access to the continuum of dementia care.

Objective: Support the development and sustainability of local, regional and statewide dementia-informed systems of care. These systems will include specialty clinics for the assessment and diagnosis of cognitive impairment, multidisciplinary care of people with dementia in the home, community, residential and nursing home environments, as well as hospitals and hospice programs.

1. Activity: Promote alternative models of peer support including phone, internet and interactive television.

2. Activity: Identify and promote the adoption of flexible, innovative respite care programs that respond to the diverse and changing needs of people with dementia and their families.

3. Activity: Explore models for developing the infrastructure to care for people with dementia in collaboration with specialists and primary care providers. For example, regional organizations designated as dementia care networks could include designated mental health and developmental service agencies, HHAs, AAAs, adult day centers or other regional dementia care providers.

4. Activity: Support access to dementia care for rural and remote regions of Vermont through the development of regional care teams that provide for the evaluation, consultation, specialty care and outreach through a hub and spokes model, such as coordinating services between regional memory centers and AAAs.

5. Activity: Increase access to geriatric and neuropsychiatric care through telemedicine, video conferencing and internet-based consultation.

6. Activity: Increase the availability of dementia-informed transportation services through activities such as:

- Travel training (training and supporting people with dementia to utilize public transportation as their cognitive abilities change)
- Door-through-door services delivered by public transit providers
- Assisted transportation
- Improved integration and coordination of public and social service transportation

A plan to address social service transportation can be found at the Agency of Transportation at:

(http://www.aot.state.vt.us/publictrans/Documents/Draft%20HSTCP%20Phase%20I%20Report.pdf)

7. Activity: Collaborate with state agencies, nursing homes and home and community-based providers to increase the capacity of the long-term care system to serve people with severe neuropsychiatric symptoms associated with dementia. Increased capacity includes specially trained staff using evidence-based models of dementia-informed care and services.

8. Activity: Develop dementia-informed hospital policies and procedures so that hospitals are well prepared to serve people with dementia who require inpatient stays.

9. Activity: Improve safety of people with dementia and the general public through the implementation of education and safety programs for older drivers.

10. Activity: Improve the coordination and delivery of care by emphasizing strong links and relationships between medical, mental health and other home and community-based services.

11. Activity: Work with hospital systems to develop special inpatient programs meeting the needs of people with dementia, for both neuropsychiatric and medical admissions.

12. Activity: Work with hospital systems to improve hospital-based care management services to assist in care coordination for people with dementia, in ambulatory care, hospital and community service settings, including home health, rehabilitation, residential and nursing home settings.

13. Activity: Work with social service providers to improve the capacity and supply of community-based case management services.

14. Activity: Work with regional medical centers and community hospitals to improve

assessment, referral and care coordination for people with dementia who are treated in emergency departments. This may include hospital-based care managers and regional care coordinators from dementia specialty clinics ("the hub") available around the clock.

15. Activity: Reevaluate the original mission of programs such as the elder care clinician program, developmental services, crisis services, adult outpatient and community rehabilitation and treatment. As appropriate, build expertise within each system to ensure dementia-informed service delivery and to expand program capacity. (Note: expanding program capacity could require changes regarding provider reimbursement).

16. Activity: Pilot a statewide, virtual or real, resource and referral center for individuals with a new or previous diagnosis of dementia and their family members. This service should provide a single point of entry for information and resources for families and consumers, such as the Vermont Aging and Disability Resource Connections.

E. Dementia Care Workforce

Workforce issues are a serious threat to much of the health care industry with significant urgency placed upon the need to expand the development, recruitment and retention of direct care works and other healthcare professionals. Healthcare workforce pressures can be attributed to two major issues; growth in the prevalence of chronic disease and the expanding aging population. Both will continue to increase in the coming decades. Consumers, families and advocates recognize the immeasurable importance of a skilled dementia care workforce and are concerned about having an adequate number of dementia-informed providers throughout the state as demand for dementia care increases.

Effective approaches to healthcare workforce planning include: 1) active professional member or employer participation, 2) accurate and relevant data on current workforce levels, 3) evidence-based or best practice interventions, and 4) workforce projection models designed to describe need in the future. Significant planning has been accomplished regarding healthcare workforce development, recruitment and retention in Vermont. It will be important to ensure that the unique needs of people with dementia and their families are included in ongoing planning and implementation efforts and that subsequent activities build upon the work and findings of Vermont's Better Jobs Better Care initiative.

Goal: Vermont has an adequate workforce to support the needs of people with dementia and their families.

Objective: Engage in initiatives which increase supply, distribution and quality of the dementia care workforce. The dementia care workforce should include conventional health care professionals and direct care workers as well as first responders, police, area agency on aging staff, housing providers and other critical workforce professions.

1. Activity: Gain active professional member or employer participation in dementia workforce development activities.

2. Activity: Improve access to dementia care specialists by including dementia training in post-graduate programs for nursing, medicine, psychiatry, neurology, psychology, social work, pharmacy and related disciplines.

3. Activity: Collect accurate and relevant data on current dementia workforce needs and develop future workforce projection models in order to target the highest need professions.

4. Activity: Promote evidence-based or best practice interventions to increase the supply, distribution and quality of the dementia care workforce such as:

- Development of standards for workforce training
- Creation of flexible training opportunities including distance learning
- Integration of dementia competencies in college and university curricula and training for health care and social service professionals
- Integration of dementia competencies into continuing education

Additional strategies identified through the following workforce documents:

1. State workforce profiles

Center for Personal Assistance Services http://www.pascenter.org/state_based_stats/xml.php?state=newhampshire

2. A Study of the Direct Care Workforce in Vermont: Status Report

http://dail.vermont.gov/dail-publications/publications-legis-studies/direct-care-workforce-vt-status-report-final-jan-30-2007

January 31, 2007

3. Report of the Vermont Healthcare Workforce Partnership: A study of the human resource needs of the healthcare industry

http://www.labor.vermont.gov/Portals/0/WF%20Development%20Council/Healthcare%20Workforce%20Report.pdf

2005

4. State Profiles

National Clearinghouse on the Direct Care Workforce

http://www.directcareclearinghouse.org/s_state_pfv.jsp?res_id=19

5. Challenges and Opportunities for the Vermont Health Care Workforce

Vermont Association of Hospitals and Health Systems

http://www.vahhs.org/lucie/Publications/Workforce%20White%20Paper.htm

F. Research

In 1994 a steering committee comprised of national public health leaders was convened for the purpose of providing a working definition of public health. The resulting Core Public Health Functions Steering Committee created the "Ten Essential Public Health Services" which has served as the fundamental framework for the responsibilities of local public health systems since that time. Essential Services for a well functioning public health system, should have a full continuum of research including "…innovative solutions to health problems ranging from practical field-based efforts to foster change in public health practice, to more academic efforts to encourage new directions in scientific research."

(http://www.cdc.gov/od/ocphp/nphpsp/EssentialPublicHealthServices.htm#es10)

Using that context, we consider research in two ways; basic research and applied research. Basic research is completed to advance knowledge, is of interest to a select group of individuals and lays down the foundation for applied research that might follow. Applied research is often completed to help solve problems of immediate concern and is geared toward larger audiences. Maximizing the synergy of basic and applied research would seem critical in successful public health efforts. The newly established Center on Aging at the University of Vermont is an important component of accomplishing the goals, objectives and activities stated below.

Goal: All Vermonters have access to credible expert opinion, latest scientific findings and promising new interventions for the prevention and treatment of dementia.

Objective: Increase dementia research by attracting more scientific investigators to Vermont, participating in grant-funded research opportunities and encouraging public participation in research studies.

1. Activity: Sponsor state-wide efforts to obtain more funding for dementia research. The Center on Aging at the University of Vermont would be a natural partner for this, but other colleges, universities and independent research centers should also be involved.

2. Activity: Work with academic partners and advocacy organizations to develop and sustain pathways by which the general public can learn about dementia research.

3. Activity: Work with academic partners and advocacy organizations to develop a cohort of older adults, individuals with cognitive impairment and families from around the state, to represent the full spectrum of Vermont's demographic and geographic diversity in longitudinal dementia studies. These individuals would have improved access to the most promising clinical trials and advance our understanding of preventing dementia and improving care for individuals and families who are already affected by this disorder.

4. Activity: Work with academic partners and advocacy organizations to replicate research-based models for the screening and management of dementia in the primary medical care setting. Evidence-based interventions for the education and support of dementia caregivers by mental health professionals imbedded in the primary care setting is an example of an effective intervention that is research-based and can be replicated in many practices throughout Vermont.

5. Activity: Improve the capacity of state and local agencies or organizations to evaluate the outcomes of their services and programs.

6. Activity: Implement the caregiver module and cognitive screening module of the Behavioral Risk Factor Surveillance System (BRFSS), the Centers for Disease Control and Prevention's national health survey.

G. Policy Changes

Both the public and policy makers value and welcome well thought out and documented information which helps their policy discussions and decision-making processes. For these audiences, however, it is difficult to find readily available supportive data, thoughtful analysis and unbiased opinions. According to the Core Public Health Functions Steering Committee which created the "Ten Essential Public Health Services" good public health systems should:

"Develop policies and plans that support individual and community health efforts" as evidenced by "systematic health planning that relies on appropriate data, develops and tracks measurable health objectives and establishes strategies and actions to guide community health improvement at the state and local levels." The committee goes on to state that "the democratic process of dialogue and debate between groups affected by the proposed health plans and policies is needed prior to adoption of such plans and policies."

While this type of collaborative process may be difficult to begin, long-term benefits include development of a common awareness between partners regarding dementia care, promoting a philosophy of collaboration which builds trust and making policy decisions more predictable and timely.

Goal: Vermont policies, regulations and laws promote improved access, quality and efficiency of the dementia care system.

Objective: Collaborative efforts are developed with state agencies, policy makers and academic centers to engage in policy-related research activities which advance Vermont's understanding and improvements in dementia care.

1. Activity: Explore new models of care and support across provider settings that enhance responsiveness to individual needs and preferences of people with dementia and their families.

2. Activity: Conduct a broader study of the existing nursing home case mix system as it relates to payment for people with dementia to ensure the current Resource Utilization Groups (RUGS) classifications and payment differentials are appropriate and reimbursement is tied to best practices for this condition.

3. Activity: Explore models and conduct financial analyses to increase utilization and access to long-term care through insurance coverage such as inclusion in employer benefit packages, pensions and universal coverage.

4. Activity: Examine the current capacity of Vermont's network of adult day providers related to the number and distribution of people with dementia and their ability to deliver quality, dementia-informed adult day services.

5. Activity: Incorporate the evaluation of cost effectiveness and financing options across all recommended policy activities.

H. Emerging Issues and Innovations

Goal: Vermont excels in providing state of the art dementia care, policies and programs.

Objective: Vermont stakeholders promote innovation and a proactive approach to emerging issues in dementia care.

1. Activity: Key state leadership (Office of Vermont Health Access, Vermont Department of Health, Vermont Department of Mental Health and Vermont Department of Disabilities, Aging and Independent Living) convenes an annual blue ribbon commission panel to strategize cross-departmental coordination of dementia-related programs. Consideration should be given to integrating this activity with existing Commissions or initiatives including the Governor's Commission on Alzheimer's Disease and Related Disorders, the Governor's Commission on Healthy Aging or the Vermont Blueprint for Health.

2. Activity: The Governor's Commission on Alzheimer's Disease and Related Disorders convenes public and private stakeholders regarding emerging and ad hoc dementia-related issues on an annual basis.

SECTION VI: NEXT STEPS

Beyond the development of this Plan, the Department of Disabilities, Aging and Independent Living, in collaboration with the Governor's Commission on Alzheimer's Disease and Related Disorders, is raising awareness, convening partners and creating opportunities to improve the systems of care for people with all types of dementia and their family members. The State Plan on Dementia provides a framework for the ongoing efforts of the Department and the Commission.

End Notes

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