

VERMONT STATE PLAN

on **DEMENTIA** *EXECUTIVE SUMMARY*



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

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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TABLE OF CONTENTS

Introduction **1**

Public Information **3**

Quality Improvement **5**

Involving Communities, Families and Consumers **7**

Dementia Care Infrastructure **9**

Dementia Care Workforce **11**

Research **13**

Policy changes **15**

Emerging Issues and Innovations **17**

INTRODUCTION

The incidence of dementia is expected to increase significantly as the population of individuals over 65 grows. In Vermont where more than 20% of the state's population will be over the age of 65 by 2020, this is of particular concern. Dementia refers to a significant intellectual decline or impairment that persists over time. Alzheimer's disease accounts for 50 to 70 percent of dementia cases and is the most common form of irreversible dementia; however, Alzheimer's is only one of many forms of dementia: in fact, there are several forms of dementia that make up the remaining 30 to 50 percent of cases.

Vermont continues to strive to meet the specialized needs of individuals 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 growth in the aging population, Vermont will not have the infrastructure necessary to continue to support this growing segment of the population, one that will be most severely 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. 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, workforce, respite services and education. The subcommittee was composed of Commission representatives, with additional representation from aging service providers. The subcommittee's process elicited feedback from direct service providers, consumers and their family members through interviews and focus groups.



INTRODUCTION

Beyond the development of this plan, the Department 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 persons with all types of dementia and their family members. The State Plan on Dementia, which is summarized here 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 executive summary, as well as a copy of the full Vermont State Plan on Dementia can be downloaded by visiting this website and navigating to the Publications and Reports section.

PUBLIC INFORMATION

According to family caregivers, dementia care professionals and other state 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:

- Memory loss is not a natural part of aging.
- Early detection and intervention can help families, caregivers and individuals 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 groundswell 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 towards campaigns and communication methods which use broad based, consistent messages through 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 to the success of both broad based, grassroots campaigns and the type of participatory communication approaches which resonate with specific segments of the public. For example, the types of approaches for young adults, businesses, or spouses, partners and children of persons with dementia should be tailored to obtain the greatest impact and effect.

- Goal:** Vermonters are adequately informed regarding dementia.
- Objective:** Design a broad based dementia and brain health public information campaign.
- Objective:** Design a grass roots information dissemination campaign.

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 professionals and consumers through the development of this Plan and spanned the broad scope of clinical and community based services supporting individuals with dementia and their families. From specialty care to 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 community, 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-based care, and promote person and family centered services.

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 persons with dementia and their families. New research demonstrates the links between empowerment, advocacy and improved quality of life. Given 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 persons 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.

DEMENTIA CARE INFRASTRUCTURE

Persons 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 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 physician and over 65% have been to their doctor for a routine physical exam within the past year. Primary care practice settings reach a very large segment of the general population which few or no other settings or service group could achieve. Given this level of contact, development of more efficient and effective integrated systems of care in Vermont's rural, remote areas that includes 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 setting.



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 health and human service, dementia informed systems of care. These systems will include specialty clinics for the assessment and diagnosis of cognitive impairment, settings providing for the multidisciplinary care of persons with dementia within the home, community, residential and nursing home environments, plus hospitals and hospice programs.

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 health-care professionals and paraprofessionals alike. Healthcare workforce pressures can be attributed to two major issues, a growth in the prevalence of chronic disease and the expanding aging population and both will continue to increase in the coming decades. Consumers, families and advocates recognize the immeasurable importance of a qualified, skilled and dementia informed healthcare workforce and are concerned about ensuring that there is an adequate volume, quality and distribution of dementia-qualified and informed workforce in the future.



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 (Vermont State Office of Rural Health and Primary Care). 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 individuals 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 persons with dementia and their families.

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

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. According to the Essential Services for a well functioning public health system, there should be 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/nphbsp/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 the most promising new therapies for the prevention and treatment of dementia.

Objective: Increase dementia-related research activities in the state by attracting scientific investigators to Vermont, increase grant-funded research and increase participation in dementia-related research that can benefit Vermont’s population.

POLICY CHANGES

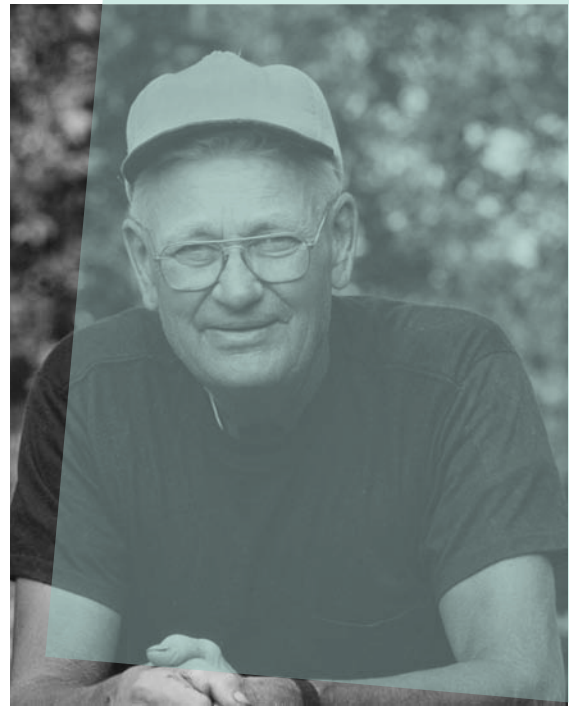
The public and policymakers often value and welcome well thought out and documented information which helps their policy discussions and decision-making processes. For these audiences, however, it is difficult to find readily available supportive data, thoughtful analysis and unbiased opinions. According 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” and promoting “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, policymakers and academic centers are developed to engage in policy-related research activities which advance Vermont’s understanding, and improvements, in dementia care.



EMERGING ISSUES AND INNOVATIONS

Scientific advances, new policies and federal changes in the approach to dementia care require a flexible, inventive as well as proactive response at the state and community level. In this environment it is critical to systematically scan the horizon for new and emerging issues in order to provide strategic guidance and increase the flow of information and exchange of ideas to improve dementia care by communities, programs and policymakers. The purpose of these activities should be to inform stakeholders of the latest trends and advances in the field of dementia with the objective of broadening the knowledge base and coordination of activities in responding to emerging challenges.



Goal: Vermont excels at the provision of state of the art dementia care, policies and programs.

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

