



Wisconsin Dementia Care System Redesign

A Plan for a Dementia-Capable Wisconsin



February 2014

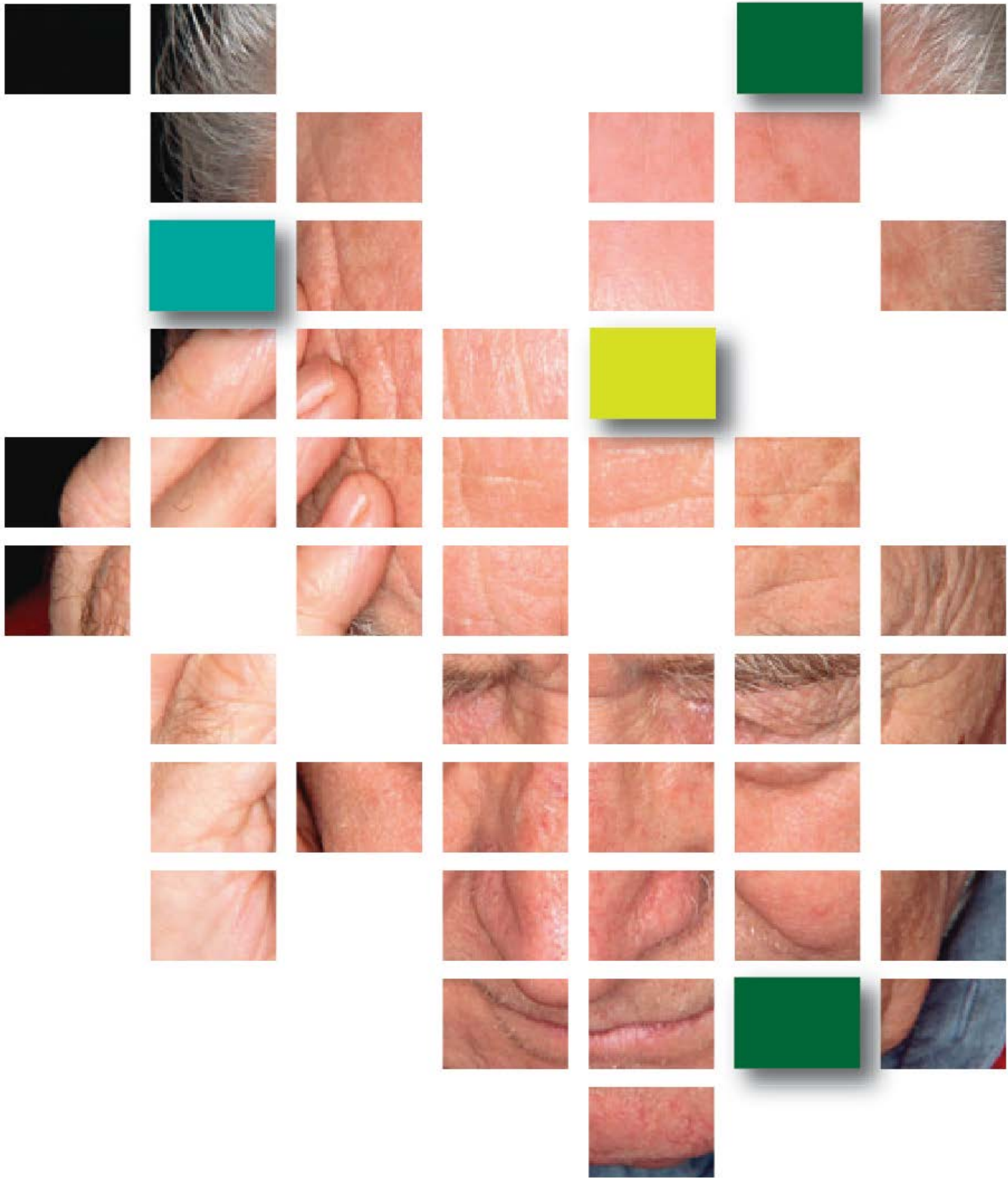


Wisconsin Department of Health Services
Division of Long Term Care
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1.0 Executive Summary

Alzheimer's disease and related dementias are already straining Wisconsin's long term care system, and the number of people affected is expected to increase dramatically as the baby boom generation ages. This sobering prospect, together with a recent decision by the Wisconsin Supreme Court in the case of *Helen E.F.* and creation of a *Special Legislative Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias*, prompted Department of Health Services Secretary Kitty Rhoades to call for a redesign of Wisconsin's dementia care system in order to provide appropriate, safe and cost-effective care throughout the course of the disease.

From the start, the Department recognized that redesigning the system of dementia care in Wisconsin would require cooperation and coordination with the many partners involved in providing dementia care services. To launch the initiative, the Department convened a Dementia Care Stakeholder Summit in October 2013. This brought together 33 key stakeholders with diverse perspectives to identify concrete ways the Department and its partners will work together to make Wisconsin more "dementia-capable" and to identify priorities. Summit participants identified six top priorities, which were then used to guide the Department's development of a "Wisconsin Dementia Care System Redesign Plan."

Following the Summit, the Department developed a draft Dementia Care System Redesign Plan (the Plan). This Plan was initially released as a draft to provide an opportunity for review and input from partners throughout the dementia care network. Stakeholder feedback was collected through a web-based survey linked to the draft plan. In addition, some individuals and organizations submitted comments directly to Department leaders. These responses were analyzed and considered in the process of creating a *final* Plan. A summary of the stakeholder input, along with a description of the process for reviewing and incorporating stakeholder input into the Plan itself, is contained in an appendix to this revised Plan.

The focus of the Plan is on steps the Department will take, working with its many partners, to address gaps in the current care delivery infrastructure and expand community and crisis services for people with dementia. The strategies have been grouped into five main subjects, with key focus areas as described as follows:

1. Community Awareness and Services:
 - Increase understanding and awareness of dementia.
 - Expand early identification and intervention.
 - Provide support for family caregivers.
2. Facility Based Long Term Care:
 - Address barriers that deter some residential care facilities from admitting and providing ongoing care for residents with challenging behaviors.
 - Continue to improve the quality of dementia care in facility settings.
 - Promote dementia-friendly facility designs.

3. Care for People with Significant Challenging Behaviors:
 - Expand capacity for crisis response and stabilization.
 - Clarify procedures for emergency protective placement.
 - Address the shortage of facilities designated to accept emergency protective placements.

4. Dementia Care Standards and Training:
 - Catalog and publicize existing dementia care training programs.
 - Develop dementia care standards for caregivers, providers and other professionals.
 - Provide additional training opportunities relating to dementia care.
 - Create incentives for compliance with staff training and other standards.

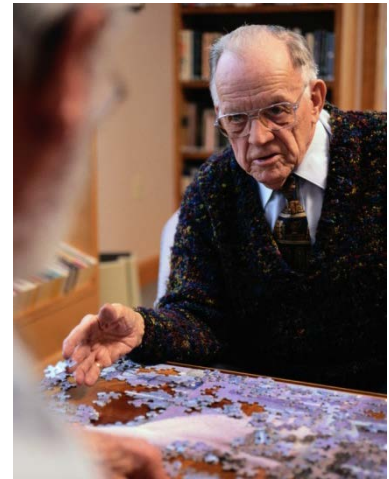
5. Research and Data Collection:
 - Develop and implement a data collection plan to facilitate quality measurement related to dementia care.
 - Conduct an inventory of dementia care providers.

A high level summary of the relationship between these strategies and the top priorities identified at the Dementia Care Stakeholder Summit in October is included as an appendix to this Plan. A high-level timeline for implementation is also provided as an appendix.

Some strategies in the Plan can be initiated immediately, while others will require additional development. Stakeholders have already contributed many implementation suggestions, and the Department will continue to reach out to stakeholders for feedback and ideas as implementation proceeds.

The Dementia Care System Redesign Plan will provide a guide for the Department's efforts to improve dementia care during the rest of the 2013-15 biennium and beyond. However, the Department considers the Plan to be a "living" document, one that will be updated and revised as implementation proceeds and lessons are learned. In addition, the Department expects that, as the priorities in the Plan are addressed, new priorities will be identified and a Plan for future improvements will be developed.

Your partnership with the Department will be essential in this effort to build a "dementia-capable Wisconsin."



2.0 Vision

The overarching goal of Wisconsin's Dementia Care Redesign is to support people with Alzheimer's disease and other dementias so each person has the highest quality of life possible consistent with the person's need for care and with the least restrictions placed on his or her personal liberty. To achieve this goal, Wisconsin's dementia care system will include:

- Care options that are sufficient and appropriate to meet the range of individual needs and preferences.
- High quality, coordinated care in all settings.
- Individualized care with the least intrusion in the person's life.
- A focus on prevention or mitigation of crisis situations that may arise from the disease.



3.0 Purpose

The purpose of the Plan is to provide a foundation for building a more dementia-capable system of care in Wisconsin, one which will move us closer to achieving the vision of providing the highest possible quality of life for all state residents with dementia. The Plan will serve as a living document, to be amended as needed by the Secretary of the Department of Health Services in order to achieve this goal.



The large numbers of people affected, the devastating impact that Alzheimer's disease and related dementias have on the affected people and their families, and the significant cost of providing care that can stretch over many years are all compelling reasons for re-examining and improving the dementia care system in Wisconsin.

A more immediate reason for undertaking the initiative is to provide a system-wide context for addressing the pressing issues raised by the Wisconsin Supreme Court's *Helen E.F.* decision and the *Special Legislative Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias*. In the *Helen E.F.* decision, issued in May 2012, the Court held that a person with dementia but with no accompanying mental illness could not be involuntarily committed for treatment under Chapter 51 of the Wisconsin Statutes, which addresses mental

illness, substance use disorders and developmental disabilities. The Wisconsin Supreme Court further held that a person with dementia as his or her sole condition would more appropriately be subject to provisions under Chapter 55, which covers the Protective Service System for individuals in need of protective placement and services. In response to that decision, a Special Legislative Committee was convened to examine the need for alternative procedures regarding guardianship, protective placement, involuntary commitment and involuntary treatment as they apply to vulnerable adults with a dementia diagnosis.

The Dementia Care Redesign is premised on the belief that the difficulty of providing care for people with Alzheimer’s disease and related dementias who exhibit challenging behaviors is best addressed within the larger context of the dementia care system as a whole. Addressing the needs of people with dementia by providing for early detection and intervention, quality care services, and crisis stabilization in home, community, and long term care settings has the potential to significantly reduce the incidence of serious challenging behaviors that result in emergency protective placements and removal of people from their residences.



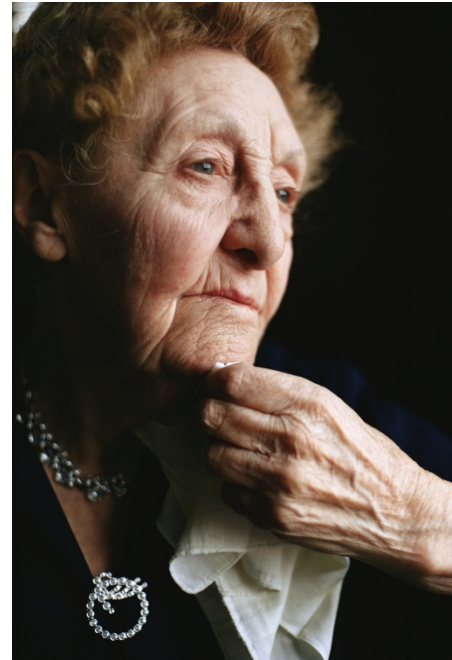
4.0 Overview of Dementia in Wisconsin

The Plan builds on the strengths of Wisconsin’s current dementia care system, begins to address existing gaps, and prepares for the anticipated growth in the number of people with dementia and the related demand for care and services. It is important to understand the dementia care system as it stands today, including: the nature of the disease and the people who are affected, the variety of arrangements and options for providing care, the numbers and types of service providers, and the roles of the various stakeholders involved. This section of the Plan provides overviews of dementia in Wisconsin, the current system of dementia care and the reasons underlying the dementia care system redesign. It also highlights key gaps and needs the system redesign will begin to address.

4.1 Alzheimer’s Disease and Related Dementias

Alzheimer’s disease is the most common type of dementia in the United States today, affecting 1 in 9 people age 65 and older. The term ‘dementia’ describes a set of symptoms of cognitive decline as a result of brain cell death caused by disease and injury to the brain. This can include declines in memory, judgment, perception, and reasoning along with other cognitive abilities. Alzheimer’s disease is a fatal illness for which there is currently no cure. Other causes of dementia include vascular events such as strokes, other diseases such as Parkinson’s disease, and other conditions that cause damage to parts of the brain.

The course of Alzheimer’s disease is one of progressive decline. The typical Alzheimer’s process begins in middle age but does not progress to the point of interfering with daily activities until people are in their 60’s, 70’s and 80’s. Early onset Alzheimer’s disease is much less common, affecting nearly 4 percent of people with dementia¹, and can begin in a person’s 30’s, 40’s or 50’s. Alzheimer’s disease accounts for 60 – 80 percent of all causes of dementia.² As more is learned about the disease, risk factors and protective lifestyle choices are being identified, along with effective strategies to manage the symptoms of the disease.



In 2013, an estimated 5.2 million Americans had Alzheimer’s disease or another form of dementia³. Wisconsin is estimated to have approximately 120,000⁴ people with Alzheimer’s disease or other dementia. Of that number, about 12,000 people are living in nursing homes and 18,000 in assisted living facilities, with the remaining people living in private residences.⁵ Family caregivers in Wisconsin provide 215 million hours of care annually for people living at home at an estimated value of \$2.5 billion.⁶ However many people living at home who say they have memory loss or confusion do not receive any help. In response to a survey conducted in 2011, 75 percent of these people reported they rarely or never received help from family or friends.⁷ Data from the Wisconsin Alzheimer’s Institute Dementia Diagnostic Clinics Network shows that 22 percent of people diagnosed with a dementia are living alone in their residence.⁸

4.2 Wisconsin’s Dementia Care System

The most common residential setting for people with dementia is a private home, followed by assisted living facilities and then nursing homes. Care for people in their homes largely comes from family members, which is supplemented by services such as adult day care, respite care and other resources for the family caregiver, such as support groups. Caring for a person with dementia has a fiscal impact on families for a variety of reasons; this includes the lost income of

¹ Alzheimer’s Association (2013) *Younger/Early Onset Alzheimer’s and Dementia* retrieved from http://www.alz.org/alzheimers_disease_early_onset.asp

² Alzheimer’s Association (2013) *What is Dementia?* retrieved from <http://www.alz.org/what-is-dementia.asp>

³ Alzheimer’s Association “2013 Alzheimer’s Association Facts and Figures”, pg. 22

⁴ Based upon dementia prevalence rates recommended by Denis A. Evans, M.D., et al. "Prevalence of Alzheimer's Disease in a Community Population of Older Persons," *Journal of the American Medical Association*, 262(18), 1989. Note that these rates may include people with or without a confirmed dementia diagnosis.

⁵ Wisconsin Dept. of Health Services at <http://www.dhs.wisconsin.gov/bqaconsumer/assistedliving/AstLvgStats.htm>, and Alzheimer’s Association of South Central Wisconsin, *Faces of Dementia in Wisconsin: An Emerging Portrait* (2013)

⁶ Alzheimer’s Association “2013 Alzheimer’s Association Facts and Figures”, pg. 35

⁷ 2011 Behavioral Risk Factor Survey, Centers for Disease Control and Prevention and WI Office for Health Informatics

⁸ Wisconsin Alzheimer’s Institute 2013 Fall Clinic Network Meeting

a caregiver who must now stay home to meet the person’s needs or the cost of paid care at home or in a long term care setting.

Agencies that provide education support and advocacy for people with dementia and their families include the Alzheimer’s Association, the Alzheimer’s and Dementia Alliance of Wisconsin, and the Alzheimer’s Support Center, among others. These agencies also work on creating awareness of systemic issues and obstacles faced by people with dementia and their families.

The Department of Health Services oversees the Aging and Disability Resource Centers (ADRCs) and county aging units, which are a resource to the public for information and assistance with long term care and aging-related issues. These two entities exist in every county and provide important services through the Older Americans Act, such as Meal on Wheels. These agencies are the front door to access Medicaid long term care programs, the Alzheimer’s Family Caregiver Support Program and the National Family Caregiver Support Program. They also provide adult protective services for “adults at risk” whose primary need is residential care and custody as a result of a condition that is likely to be permanent, including degenerative brain disease such as Alzheimer’s disease and related dementias, and who have experienced, are experiencing, or are at risk of experiencing abuse, neglect, or financial exploitation.

The Department also administers Medicaid fee-for-service and Medicaid long term care home and community-based waiver programs, which provide care and services to people with dementia who cannot afford supports on their own. As of December 31, 2012, there were 9,507 people with a diagnosis of dementia being served in Wisconsin’s long term care Medicaid waiver programs.⁹ Approximately 20 percent of Family Care members, 25 percent of Family Care Partnership members and Community Options Program (COP) enrollees, and 6 percent of IRIS program participants have a diagnosis of dementia.¹⁰

The Department also oversees licensed assisted living facilities and nursing homes, home health agencies, adult day care facilities and hospitals. Of the 28,514 people residing in nursing homes at the end of 2012, 12,961 (45%) had a diagnosis of dementia.¹¹ In the final stages of Alzheimer’s disease, hospice care can provide palliative care for people as they near the end of life and can often provide the care in the settings in which the people reside.



The Department also oversees county crisis response services for people with dementia, a developmental disability, mental illness or

⁹ Wisconsin Department of Health Services, Division of Long Term Care (Long Term Care Functional Screen data)

¹⁰ Wisconsin Department of Health Services, Division of Long Term Care (Long Term Care Functional Screen data)

¹¹ Wisconsin Department of Health Services, Division of Quality Assurance (Minimum Data Set - nursing home data)

substance use disorder. Previously, the most common settings for care for people with dementia in crisis were inpatient mental health units and treatment facilities. When people with dementia exhibited behavior deemed to be a threat to the safety of themselves or others around them, they were often admitted to these care settings for treatment intended to manage the behavior. This was commonly accomplished through the Chapter 51 Emergency Detention process. However, after the Wisconsin Supreme Court's decision in *Helen E. F.*, the use of inpatient mental health units and treatment facilities is no longer an option for people in crisis who have a dementia diagnosis and thus no longer qualify under Chapter 51 mental illness criteria.

4.3 Recent Developments



In 2010, the Department partnered with the Helen Bader Foundation to conduct a series of lecture and listening sessions around the state on various topics related to dementia. These sessions, called “A Hand in the Plan,” were accompanied by a series of surveys to be completed by anyone interested in dementia care in Wisconsin. Information from the sessions and the surveys has helped guide the state’s response to dementia and the creation of the Dementia Care Specialist positions at several Aging and Disability Resource Centers.

The Dementia Care Specialists provide cognitive screening for early detection of cognitive change, assist people in connecting with their physicians for diagnosis, and provide evidence-based programs and support for people with dementia and their caregivers. The Dementia Care Specialist program is currently being piloted in five ADRCs.

The stories of two people with Alzheimer’s disease highlight the need for the Dementia System Redesign. The

Southeastern Wisconsin Chapter of the Alzheimer’s Association convened the Challenging Behaviors Task Force in 2010 in response to the concerns about the circumstances of the death of Richard Peterson. Around the same time, a woman with dementia in Fond du Lac County

was appealing the decision to have her placed in a mental health treatment facility due to her behavior.

Richard Peterson Story

Richard Peterson was an 80 year old man with Alzheimer's disease living in a long term care facility in Milwaukee County. His difficulty began in the dining room of the facility, where he was having dinner with his wife, when he insisted on packing up and leaving the facility. As his wife tried to calm him, he struck out and hit her. He was immediately moved to a special care unit at the facility, and changes were made to his medications. After another week, and two other incidents of challenging behavior (wandering into another person's room and refusing to leave, and at another time picking up a chair in a threatening manner), the decision was made to hospitalize him. Due to the non-availability of facility beds in the preferred setting, and confusion between local crisis intervention and protective services systems, he was transferred to two different hospitals for treatment before being placed at a mental health complex under Chapter 51.

The trauma of multiple transfers appeared to take a toll on his health, and shortly after arriving at the mental health complex Mr. Peterson developed pneumonia and was transferred to yet another hospital. He died shortly afterward. The Challenging Behaviors Task Force was convened after his death to bring together interested parties to develop ideas to improve the care system and avoid similar situations in the future.

Helen E.F. Story

Helen E.F. was an 85-year-old woman with Alzheimer's disease who had lived in a nursing home in Fond du Lac for six years. When she began to exhibit agitated and aggressive behavior, including striking out at caregivers and refusing meals and medication, she was removed from the nursing home. Eventually, the court issued an order involuntarily committing Helen E.F. to a locked psychiatric unit for up to six months.

Helen E.F. appealed that decision. Ultimately, her case reached the Wisconsin Supreme Court, which stated that a person with a dementia diagnosis who does not also have a qualifying Chapter 51 illness is not a proper subject for commitment or treatment under Chapter 51, the State Alcohol, Drug Abuse, Developmental Disabilities and Mental Health Act.

Because Helen E.F.'s disability was likely to be permanent and she was not capable of rehabilitation and treatment as required by Chapter 51, Helen E.F. was found to be a proper subject for protective services under Chapter 55, the Protective Services System, the focus of which is where the individual will live and what services he or she will receive. By using Chapter 55, Helen E.F. would be allowed to be cared for in a facility more narrowly tailored to her needs and provided with additional protections.

The State appeals court determined in the case of *Helen E.F.* that inpatient mental health treatment facilities were not appropriate settings for people with a dementia only diagnosis. The appellate court decision was appealed but the decision was upheld by the State Supreme Court in May of 2012.

Prior to the Supreme Court decision, the Southeastern Chapter of the Alzheimer's Association requested a Legislative Council study of Chapter 51, the State Alcohol, Drug Abuse, Developmental Disabilities and Mental Health Act, and Chapter 55, the Protective Service System. The Legislative Council agreed to take up the topic in April and began meeting in August of 2012. During the work of the Committee, the Department offered an option to redesign the dementia care system in lieu of the legislative changes being considered. A letter was submitted to the Committee stating the Department believed the proposed changes to the law were not required, and instead suggested an alternative approach that would create an improved system of care as the solution to these issues.

The Department proposed that it spend two years collecting and analyzing data, researching best and promising practices, and developing a more comprehensive approach to dementia. The Department's first step was to involve critical stakeholders in identifying top priorities for a system redesign plan.



4.4 Key Gaps and Needs

The Department worked with The Johnson Foundation at Wingspread to co-host a Dementia Care Stakeholder Summit in early October 2013. The purpose was to engage experts and representatives of key stakeholder groups in a collaborative effort to identify key gaps and needs in the care system. Through a structured, small group discussion process, participants identified efforts that work, as well as areas for improvement, in the state’s existing system of dementia care, the characteristics of an ideal system of care, strategies for making the current system more “dementia capable,” and a short list of the most critical areas for prompt intervention by the Department. Those top priorities include:

- Increase community awareness of dementia issues and of the resources available to provide support to people with dementia and their family caregivers.
- Expand the use of dementia care specialists and case managers to coordinate care, help with transitions, and work with people and their families throughout the disease process.
- Revise state regulations to allow for “safe harbors” that let facilities care for residents who engage in challenging behaviors in place with less fear of liability or regulatory penalties.
- Create fiscal and systemic incentives for best practices.
- Expand mobile crisis teams to assess and diffuse difficult situations and help avoid the need for more restrictive placement.
- Create placement facility capacity to care for people with complex and challenging behavior needs.

The priorities identified by Summit participants have served as the foundation for the Department’s subsequent work in developing a plan intended to make Wisconsin a more “dementia-capable” state. The full Summit report can be found at <http://www.dhs.wisconsin.gov/publications/P0/P00563.pdf>.



5.0 A Dementia Agenda for Wisconsin

The Department's plans for strengthening Wisconsin's dementia care system have been organized into five broad categories: community awareness and services; facility-based long-term care; care for people with significant challenging behaviors; dementia care standards and training; and continuing data collection, research and analysis. The strategies in each of these areas are described below.

5.1 Community Awareness and Services

Three out of four people with dementia live at home in their local communities, and of these, 22 percent live alone.¹² Many people are embarrassed and confused by the loss of abilities that accompany dementia and do not know where to turn when they or their loved ones can no longer manage without assistance. Support from the community can be an important resource in the dementia care system by helping to delay or prevent the need for institutional care and by promoting quality of life for people with dementia and their caregivers.

5.1.1 Increase Understanding and Awareness of Dementia

One of the barriers to understanding and awareness of dementia is stigma. The Department believes that stigma mitigation is a product of families that better understand dementia, appropriately trained care providers, informed public safety agencies, and greater community awareness that enables persons with dementia to be naturally accepted as part of the community fabric. The more knowledge people have about dementia, about how to interact with and support people with the condition, and about the resources that are available to help, the greater the likelihood that people with dementia and their families will be able to manage in the home and community settings that people typically prefer.

Related Strategies

- **Expand the Dementia Care Specialist Program in Aging and Disability Resource Centers (ADRCs).**

Dementia Care Specialists in Wisconsin's ADRCs play a variety of roles in promoting community awareness and access to services. ADRCs provide community education, mobilize community resources, help people identified through the screening process obtain a diagnosis and other support, conduct early intervention programs, and assist family caregivers. They also consult with law enforcement, Adult Protective Services (APS), and others who need information regarding dementia-related issues. Currently, the Department funds Dementia Care Specialists in five different ADRCs. The program has received very positive evaluations. The Department will expand the Dementia Care

¹² Wisconsin Alzheimer's Institute 2013 Fall Clinic Network Meeting

Specialist program to another 10 ADRCs with current funding, and may seek funding in future budget cycles to make the service available statewide.

- **Strengthen Department and ADRC information and referral resources to facilitate access to dementia care resources in the community.**

This strategy will increase the public's access to information about dementia and the community resources that are available to help, including such things as diagnostic services, support groups, caregiver training, respite care, in-home care, alternative placements, advanced care planning assistance, and sources of financial support. The strategy involves:

- *Data Base Enhancement.* The Department of Health Services will encourage ADRCs to review and, where necessary, update the information in their resource databases to ensure that the information and assistance they provide to people with dementia, their families and caregivers is current and complete. Resource information will also be incorporated in a statewide resource database that can be accessed online by caregivers and other members of the public.
- *Dementia Web Page Development.* The dementia page on the Department's website (<http://www.dhs.wisconsin.gov/aging/Genage/alzfcgsp.htm>) will be redesigned to make it more user friendly and to more clearly distinguish information intended for consumers from that aimed at facilities, other service providers and professionals. Consumer information would, among other things, include dementia basics, communications strategies, criteria to assist people when choosing a dementia care facility, and ADRC contact information. Professional information would include information on best and promising practices for facility-based care, model protocols, training videos, and other skill building resources.
- *Outreach to Increase Referrals to the ADRC.* ADRCs will be directed to outreach to a variety of agencies and organizations in their communities regarding the assistance an ADRC can provide to people with Alzheimer's disease and related dementias and to encourage referrals to the ADRC. Agencies contacted will include: Adult Protective Services; law enforcement; county mental health programs; primary care physicians and clinics, hospitals, nursing homes and assisted living facilities; local Alzheimer's organizations; and the United Way and other similar community groups.

- **Increase the Capability and Capacity of Managed Care Organizations (MCOs) to provide dementia-capable services.**

Most Family Care members live in home and community settings with MCOs contracting with a wide variety of care providers. Therefore, MCOs have an important role to play in promoting dementia-capable community services. This strategy will ensure appropriate, dementia-capable care for MCO members and will promote the MCO to use its

relationship with its provider network to improve the dementia care available to the community at large. The strategy involves:

- *MCO Dementia Care Leads.* The Department will ask MCOs to designate one, or more, dementia-trained care leads to work with the MCO's care management teams and provider networks to ensure that their services are dementia capable.
 - *Dementia-capable MCO Provider Networks.* The Department will ensure MCOs work with their provider networks to develop dementia care skills, including skills needed to prevent situations involving challenging behavior from escalating to a crisis level.
 - *Dementia-related Assessment and Care Planning.* The Department will work with MCOs to develop best practice guidelines for assessment of dementia related needs and care planning to incorporate effective treatment and support strategies for members with dementia.
 - *Enhancements to the Long Term Care Functional Screen.* The Department will continue its effort to develop and test enhancements to the Long Term Care Functional Screen in order to better identify issues related to dementia and behavioral health that may impact care needs.
- **Promote dementia friendly communities.**
Several communities have successfully organized community-wide responses to dementia, including law enforcement, transportation providers, medical providers, businesses and the general public. Participants have been trained to recognize the signs of dementia, to communicate effectively with people with dementia, and to locate resources for assistance. The Department will promote the concept of dementia friendly communities and the ADRCs Dementia Care Specialists will help to organize these efforts.
 - **Partner with private and public employers to support dementia-capable work environments.** The Department will encourage public and private employers to provide information to employees on dementia and on resources available to help individuals with dementia and their family caregivers.
 - **Engage the medical community in the dementia initiative.** Their doctor is the first place many people go for information about dementia. The Department will work with partner agencies, such as the Wisconsin Medical Society, Wisconsin Hospital Association, and Wisconsin Alzheimer's Institute, to provide continuing education on dementia, and disseminate other information, such available community resources, to the medical community.

- **Engage public health departments in the dementia initiative.**
Public health departments play an important role in health promotion and chronic disease prevention. After consulting with local public health departments, the Department of Health Services will incorporate strategies for addressing dementia in the public health context and will promote and encourage the involvement of local public health agencies in efforts such as organizing local dementia awareness campaigns, educating the public about lifestyle and disease management techniques that are helpful for people with dementia and their family caregivers, identifying underserved populations, and advocating for needed supports in the community.
- **Promote the use of the Department of Public Instruction dementia curriculum.**
In 2011, the Department of Health Services partnered with the Department of Public Instruction (DPI) to develop a dementia curriculum for use in health classes in middle and high schools. The intent of the curriculum is to give children a better understanding of dementia, which can help reduce the social stigma associated with the disease. In addition, it is estimated that of households caring for someone with dementia, 26% also have a child under age 18 living in the residence.¹³ The curriculum helps children whose family members have dementia learn about positive ways of interacting. The Department will continue to work with DPI to encourage broad use of the dementia curriculum in middle and high school health classes.
- **Ensure that community based dementia services are culturally competent.** The Department will work to ensure that community awareness and services strategies incorporate culturally competent practices. Minority communities, including ethnic and racial communities, Native American Tribes, and limited English proficiency communities are at an increased risk for developing dementia and face unique challenges that must be addressed to ensure that all communities have equal access to appropriate dementia care and services tailored to their needs.

5.1.2 Facilitate Early Identification and Intervention.

People obtaining a timely diagnosis can allow for interventions and lifestyle changes that have the greatest potential impact on the disease process. Interventions for both the person with dementia and family caregivers can help people manage symptoms of the disease, maintain functional abilities, and enhance the ability of families to provide care at home for as long as possible.

Related Strategies:

- **Expand capacity for dementia screening and diagnosis.**
Cognitive screening is used to identify deficits in one or more areas of cognitive function, including memory, abstract thinking, attention and reasoning. Screening can

¹³ Alzheimer's Association "2011 Alzheimer's Association Facts and Figures", pg. 25

identify early signs of dementia, along with other potentially treatable causes of cognitive impairment. When deficits are detected and with the person's permission, the person is referred to a physician for examination and possible diagnosis. Diagnosis at an early stage in the disease allows interventions to have the greatest impact on the disease trajectory and in managing symptoms. It also gives the person and family time to plan for the future. Once a diagnosis is obtained, the individual and family can be connected to appropriate services and supports, including the ADRC. In order to expand capacity for screening and referral for diagnosis, the Department will do the following:

- *Cognitive Screen Training.* Continue to provide web-based and in-person training on how to screen for cognitive impairments to ADRC, MCO, and county and tribal aging, long term support and adult protective services staff. To date, more than 400 people have been trained.
 - *Outreach to Physicians.* Continue contractual support of the Wisconsin Alzheimer's Institute (WAI) and its efforts to expand the WAI-affiliated Dementia Diagnostic Clinic Network. Efforts include providing ongoing consultation and mentorship to the existing network and working to extend the impact of network clinics into the broader community. The Department will also promote the availability of the Dementia Diagnostic Clinics Network.
 - *Support ADRC Cognitive Screen Performance, Referral and Follow-Up.* Partner with provider associations, dementia organizations, and community organizations to increase referrals to the ADRCs for cognitive screening, information, and referrals. The Department will also encourage ADRCs to inform the public about the availability of screening services and follow-up assistance to include time to discuss the diagnosis. ADRC outreach and marketing will be expanded over this period to underscore the opportunity to receive information and assistance as well as options counseling to support care planning, and to facilitate access to any needed services.
- **Provide early stage programming and support.**

Early stage programming can improve people's well-being, help people with dementia retain skills, and help caregivers continue to support their family members at home and in the community. This strategy continues and expands the provision of evidence-based interventions and other promising models of dementia-related programming, such as Language-Enriched Exercise Plus Socialization (LEEPS), Memory Care Connections (also known as the New York University Caregiver Intervention), Powerful Tools for Caregivers®, Savvy Caregiver, Memory Cafes, and others. The Department will work with ADRC staff, including Dementia Care Specialists, other organizations, and public health departments to conduct the program. The Department will coordinate with researchers, clinical specialists, and service providers to identify emerging, promising practices, develop and research best practice models, and share information.

5.1.3 Provide Support for Family Caregivers

Eighty percent of care provided to people with dementia living in the community is provided by unpaid caregivers, most often family members.¹⁴ Acknowledgement of unpaid caregivers is essential to the dementia system redesign. Family caregivers often lack sufficient understanding to be able to appropriately respond to the needs of a family member with dementia or to recognize their own need for support. Many spouses and adult children whose parents develop dementia do not think of themselves as caregivers. They provide care day after day, often unaware of the physical and mental stress being placed upon them.

In cases of degenerative disease such as Alzheimer's, family caregiver stress increases as the disease progresses. If a family caregiver does not understand the disease trajectory, or has not been taught techniques to deal with their loved one's difficult behaviors, then caregiver depression and physical illness can result. It is not uncommon for a spousal caregiver to become seriously ill or die before the person with dementia dies, often resulting in crisis as family and friends are forced to make sometimes uninformed and costly decisions regarding ongoing care and service. Programs to support family caregivers can significantly delay the need for institutional care and reduce costs to the Medicaid program.

Related Strategies:

- **Expand access to caregiver education and support programs**

The Department's Office on Aging currently partners with the Wisconsin Alzheimer's Institute, UW-Madison School of Medicine and Public Health, county aging units, ADRCs, and Alzheimer's support organizations to implement a variety of evidence-based programming, including a highly successful program for family caregivers called Memory Care Connections. Memory Care Connections teaches families proven methods for decreasing caregiver burden and burnout, while strengthening formal and informal care networks. Caregivers who complete this program delay the need for institutionalization of the person with dementia, by an average of 18 months. This represents a significant cost savings to the family and often to the State's Medicaid program. Memory Care Connections is currently available through the five Dementia Care Specialists. The Department will be expanding availability of the program to 10 additional ADRCs initially, and will work with all ADRCs to make the program available statewide.

Other evidence-based programs, such as Savvy Caregiver and Powerful Tools for Caregivers, are available in some areas of the state. However, none of these programs are available statewide. Access to these programs will be increased by adding Dementia Care Specialists in ADRCs, as well as by emphasizing "caregiver awareness" as part of general ADRC outreach efforts. These strategies will help inform people about health risks associated with caregiving and increase their awareness of the programs and services that are available in the communities. The Department and ADRCs will also

¹⁴ Alzheimer's Association "2013 Alzheimer's Association Facts and Figures", pg. 29

work to expand their partnerships with health care and community organizations to fund or provide caregiver support programming, so that all Wisconsin caregivers have access to at least one of these evidence-based programs. Additional options for in-home caregiver support will be explored to meet the needs of caregivers who are unable or do not want to attend classes in-person.

- **Expand and update the Alzheimer’s Family Caregiver Support Program (AFCSP)**

The Alzheimer’s Family Caregiver Support Program (AFCSP) was enacted by the Wisconsin legislature in 1985. This established Wisconsin as a national leader in caregiver education and support. Families with access to resources to purchase respite care and other services are able to care for their loved ones at home. Although needs have grown dramatically due to population growth since 1985, funding for AFCSP has been reduced. Over time this has resulted in some smaller Wisconsin counties receiving such limited funds that only one or two families can be served by the program each year. There is also very limited access for tribal members, who must access AFCSP through local county offices.

Eligibility guidelines for AFCSP have not been updated. For example, income eligibility requirements remain at 1985 levels, which means that fewer families are eligible to participate. The amount of financial support available through the program remains at \$4,000 per family, per calendar year, an amount which is inadequate to support a person with dementia at home.

Under this the Department will work to accomplish the following:

- *Revise the maximum per family allowance and income eligibility requirements for AFCSP.* Updating these program parameters to today’s cost of care standards will better enable Wisconsin families to delay costly nursing home and assisted living admissions.
- *Increase awareness of AFCSP and the National Family Caregiver Support Program (NFCSP).* Part of the Older Americans Act Title III program, the NFCSP provides support similar to AFCSP for family caregivers of all types, including those caring for someone with dementia. The Department will have ADRCs assign Dementia Care Specialists the responsibility of increasing awareness of the AFCSP and NFCSP through community outreach and marketing. Getting people to self-identify as caregivers is the first step to expanding caregiver capacity.
- *Encourage greater coordination between the AFCSP and NFCSP programs.* Closer coordination between these two complementary programs at the local level will improve efficiency, maximize the utilization of each program and ensure that families have access to all potentially available sources of support.

- *Increase funding for AFCSP.* The Department will review options for increased funding for the Alzheimer’s Family Support Program to keep pace with the growing number of older adults and inflation in service costs.
 - *Establish a Tribal AFCSP allocation.* The Department will survey tribal aging directors to determine the number of elders with dementia, and establish a Tribal AFCSP allocation.
- **Use volunteer programs to provide support for people with dementia and their family caregivers.**
 Volunteers extend needed community services at a low cost to state and local governments, and for free or at an affordable cost, to the people who need and use the services. Examples of successful volunteer programs include respite services, adult day programs, caregiver support groups, and early stage programs such as LEEPS. This strategy provides grant-funding for Aging Offices or ADRCs to plan and implement volunteer-based services for family caregivers and people with dementia using best practice approaches. Activities involved in implementing this strategy include:
 - Develop additional examples of volunteer-based programs for family caregivers of people with dementia.
 - Develop a toolkit for replication of best practice programs.
 - Obtain funding for and awarding grants to Aging Offices or ADRCs to establish volunteer programs. Grant funds are needed to pay a volunteer coordinator to recruit, train and supervise the volunteers and manage the program.
 - Monitor implementation and progress of recipient organizations.



5.2 Facility-Based Long-Term Care

Approximately one in four Wisconsin residents with dementia are cared for in a facility based setting – a nursing home, community based residential facility (CBRF), residential care apartment complex (RCAC) or adult family home (AFH). As of December 31, 2012, Wisconsin nursing homes reported 12,961 residents, or 45 percent of their total resident population, as having Alzheimer’s disease or a related dementia. Based on national statistics, approximately 40 percent of assisted living facility residents also have dementia.¹⁵ Facilities are able to care for people at all stages of the disease. People generally enter a facility when they can no longer be cared for in the home setting. These residents tend to be those whose care needs and risk of challenging behaviors are higher.

Nursing homes and assisted living facilities are regulated by the Wisconsin Department of Health Services’ Division of Quality Assurance, which licenses and certifies facilities, conducts regulatory reviews on a periodic basis, and in response to complaints or finding of deficiencies, orders plans of correction and imposes fines and other penalties.

5.2.1 Address Barriers that Deter Some Facilities from Admitting and Providing Ongoing Care for Residents with Challenging Behaviors.

The risk of severe penalties as a result of providing care for residents with dementia who exhibit significant behavioral symptoms and may be physically abusive to other residents is a reason cited by facilities for not admitting people with these needs. Nursing homes that do not promptly respond to violent or aggressive behaviors and implement interventions risk a federal finding of harm or immediate jeopardy and the possible imposition of a Civil Money Penalty (CMP). While the number of immediate jeopardy citations for residents who have harmed other residents is relatively small, the amount of the penalty can be large and could exceed several thousand dollars based on the length of time other residents were harmed by a resident who suffers from Alzheimer’s disease or related dementia. Assisted living facilities that do not act quickly and take corrective action when a resident becomes combative also face state citations and significant enforcement remedies, including forfeiture penalties and orders not to admit any new or additional residents.

Facilities are not typically cited because a resident harmed another resident, but rather because the home did not properly assess the resident and implement the plan of care or did not re-evaluate the care plan after the resident became aggressive. Nonetheless, many facilities believe it is not worth the risk to admit or retain and care for residents with challenging behaviors.

¹⁵ 2010 National Survey of Residential Care Facilities, U.S. Dept. of Health and Human Services

Related Strategies

- **Identify factors leading to citations related to challenging behaviors and educate providers about how to prevent these circumstances.**

The Department will conduct a comprehensive study of all immediate jeopardy citations that include findings relating to nursing home residents with behavioral symptoms and, for each citation, perform a root cause analysis to identify what led to the deficiency. Causes may include inadequate staffing, lack of training or other issues. Common care omissions included in the immediate jeopardy findings will be identified, together with their underlying causes. This information will be documented and shared with nursing homes, advocates, and nursing home trade associations to provide the basis for quality improvement efforts. A similar study will be conducted of serious violations issued against assisted living facilities related to residents with behavioral symptoms. The results of the review will be shared with assisted living facilities, advocates and trade associations to assist facilities improve their program.

- **Develop guidelines to address the causes of regulatory violations relating to challenging behaviors.**

The Department will develop best practice guidelines for how to effectively care for residents with behaviors that may threaten or endanger other residents. Best practice guidelines will emphasize consistent staff assignments, ongoing staff training, and assessment for underlying causes of behaviors such as pain, physical illness, or medication interactions. The guidelines will include a decision tree for facilities to use when facing a challenging situation, starting with problem identification, assessment of the behavior, development of a multi-disciplinary care plan that addresses behavioral issues, regular evaluation of the effectiveness of the plan, and trying new interventions when needed. Information about best and promising practices will be shared with facilities and be the subject of Department provided trainings through its annual FOCUS conferences and DQA email listserv announcements.

More detailed strategies relating to this approach are described in the section of the plan dealing with standards and training.

- **Seek federal flexibility for nursing homes that adhere to best practice guidelines.**

Some behaviors are not predictable and preventable. The Department will work with representatives from the Centers for Medicare and Medicaid Services (CMS) to give states greater flexibility in applying immediate jeopardy citations to nursing homes that follow best practice guidelines for dealing with challenging behaviors. As part of this process, the Department will identify any concerns that CMS may have and incorporate their suggestions into the best practice guidelines. However, the Department will not seek to hold dementia care facilities to a lesser standard than that for other long term care providers.

5.2.2 Continue to Improve the Quality of Dementia Care in Facility Settings

Most facilities provide good care for their residents. The Department found no deficiencies or violations in over half of the assisted living surveys conducted by the Division of Quality Assurance in 2012, and fewer than 20 percent of the surveys found deficiencies that were severe enough to result in regulatory penalties or enforcement. Similarly, fewer than 20 percent of all assisted living facilities accounted for all the complaints received by the Department in 2012.

No deficiencies or violations were found in 43 percent of the nursing home surveys conducted by the Division of Quality Assurance from October 1, 2012, through September 30, 2013; another 36 percent of nursing home surveys had 5 or fewer citations. Of the 617 surveys with citations, only 6 percent had 1 or more findings of substandard quality of care. Similarly, 22 percent of all nursing homes account for two-thirds of all complaints received by the Department and 55 percent of homes had no complaints or only 1 complaint.

However, regulations alone cannot guarantee quality. Regulations establish minimum requirements to ensure health and safety; they are not designed to address best practices in caring for residents with dementia or other specific needs. Neither Wisconsin's nursing home nor its assisted living regulations contain special requirements for Alzheimer's disease or other dementia care units. Most facilities provide good care; however, some facilities provide inadequate services related to dementia and behavioral health care and could improve.

Wisconsin currently has two successful public-private partnerships to improve the quality of facility-based long term care – the *Wisconsin Clinical Resource Center* (Resource Center) for nursing homes and The *Wisconsin Coalition for Collaborative Excellence in Assisted Living* (Coalition).

The *Wisconsin Clinical Resource Center* was created by the Center for Health Systems Research and Analysis (CHSRA) at University of Wisconsin-Madison under the joint sponsorship of the Department, the Wisconsin Health Care Association, and LeadingAge Wisconsin. It provides web-based resource information, tools and training modules on a variety of topics. Some of these, including "Challenging Behaviors," "Dementia and Distressed Behaviors," and "Review of the Care Process: Getting to the Root of the Matter," address issues related to care of residents with dementia.

The *Wisconsin Coalition for Collaborative Excellence in Assisted Living* focuses on internal quality assurance and quality improvement programs that are developed by the provider associations and approved by the state's regulatory and funding agency, the Department of Health Services. Each of the state's four assisted living provider associations has developed quality programs. These include LeadingAge Wisconsin's CBRF and RCAC Quality Improvement Network, the Residential Services Association of Wisconsin's Star Quality Accreditation, the Wisconsin Assisted Living Association's

Diamond Accreditation Program, and the Wisconsin Center for Assisted Living's Performance Excellence in Assisted Living Program.

There are also a number of examples of best practices employed by care facilities in Wisconsin. One example is the Music and Memory program, which helps nursing home residents with Alzheimer's disease and related dementias find enjoyment and connection through personalized music. Another example is Serial Trial Intervention, an evidence-based model for identifying and treating the underlying causes of agitated and disruptive behaviors in people in the advanced stages of dementia.

This strategy aims to improve the quality of dementia care by building on current successes and relationships within the context of existing regulations.

Related Strategies

- **Provide staff training opportunities.**

Staff who are trained in dementia care and have skills to respond to challenging behaviors are able to provide better quality care. This strategy encourages facilities to provide dementia training for their staffs, adopt best or promising practices for dementia care, and voluntarily adhere to Department-approved training and other dementia care standards, including those that build cultural competency. This strategy involves:

- Encouraging facilities to share information about, and take advantage of, existing training opportunities.
- Developing a comprehensive dementia care training curriculum, with components tailored to different types of caregivers and providers, and making the training widely available to facilities and other providers (see "Standards and Training").

- **Disseminate information on promising dementia care practices.**

A number of facilities and their professional associations are already working on ways to improve dementia care. This strategy aims to build on this work by sharing the information more widely through the *Wisconsin Clinical Resource Center* and the *Wisconsin Coalition for Collaborative Excellence in Assisted Living*. This strategy involves:

- *Creating access to best and promising practices developed by facilities.* Facilities will be encouraged to submit information about successful programs they have developed to the Resource Center and Coalition so that they can be shared with others. Information to be shared includes: training materials, assessment tools and other practices or procedures that have resulted in good outcomes for residents with dementia. Practices that reduce the use of antipsychotic or anti-anxiety medication, reduce agitation, and provide a better quality of life for residents will be the primary focus.

- *Promoting best and promising practices through regional training and information sharing workshops for facilities, trade associations, counties, tribes, advocates and Department staff.* Workshops will highlight best and promising practices and facilitate collaboration among stakeholders. Information from the workshops will be published on the Coalition and Resource Center websites.
 - *Providing technical assistance and mentorship opportunities.* Nursing homes with positive outcomes for residents with dementia will be identified through analysis of the Minimum Data Set (MDS) data. DHS may identify high performing facilities and establish mentorship programs to link facilities that are willing to serve as a mentor with those that would like to improve the care they provide.
 - *Exploring options for continued support for the Wisconsin Clinical Resource Center and the Wisconsin Coalition for Collaborative Excellence in Assisted Living to further their mission.*
- **Explore incentives for facilities that adopt best or promising practices and show positive outcomes.**
Providing quality care costs money. This strategy looks to develop a closer relationship between the care provided and the reimbursement they receive through the state’s Medicaid program. It involves:
 - Identifying possible financial incentives for high quality dementia care through the Medicaid fee-for-service (FFS) rate-setting methodology for nursing home reimbursement. One possibility would be to expand the current Medicaid incentive for nursing homes providing care for residents with behavioral and cognitive impairment challenges.
 - Encouraging MCOs to include dementia care expectations in contracts with nursing homes and assure that acuity-based rates with assisted living facilities adequately address issues of dementia-capable care.
 - **Promote adoption of voluntary standards for dementia care.**
Currently there are no generally accepted standards for dementia care provided by home care agencies or facility-based providers in Wisconsin. Voluntary standards for facility-based dementia care will be developed as part of a more comprehensive standards and training initiative that is described later in this plan document. [See section 5.4 -- “Standards and Training”].

5.2.3 Promote Dementia-Friendly Facility Design

Many assisted living and nursing facilities are designed in ways that are not dementia-friendly. Wisconsin’s nursing homes are aging, with many facilities designed and built three, or more,

decades ago. As a result, many facilities feature physical layouts that do not reflect current advances in understanding of how the physical attributes of a facility can support or hinder care. The underlying resident demographics have also changed since many of these facilities were originally designed. Overall, residents are older, frailer, and more likely to have a dementia diagnosis. All facility types that provide service to people with dementia will be encouraged to adopt dementia-friendly design elements, including nursing homes, CBRFs, adult family homes and adult day care facilities.

A variety of dementia-friendly designs have been developed nationally, including the Green House Project, the Society for the Advancement of Gerontological Environments (SAGE), and the Eden Alternative. There are additional efforts to consider dementia-friendly design, at the University of Wisconsin-Milwaukee, with members from the Architecture, Planning, Social Welfare and Occupational Therapy program working with community representatives to set policies and programs through the Institute on Aging and the Environment. Some design principles, such as conversion of large nursing facilities into smaller households, can require significant capital investment. Others, such as redesigning common and outdoors areas to be more inviting and comfortable, require smaller investments.

Related Strategies

- **Encourage facilities to adopt design elements known to support dementia care.**
DHS will work with stakeholders to identify elements of a dementia-friendly environment, including elements that could be implemented incrementally or as major redesign ideas. Information regarding these design elements will be disseminated through regional dementia care workshops and published on the Resource Center, Coalition and Department of Health Services websites.
- **Provide financial incentives to encourage facilities to undertake dementia-capable design projects.**
The Department's Nursing Home Modernization Program includes dementia-capable design criteria as part of the evaluation process. Nursing home providers may request a special Modernization Property Incentive Medicaid rate adjustment to support construction projects related to renovation or replacement of existing buildings. The twin goals of the Modernization Property Incentive are to support the use of resident-centered facility design concepts to update and improve nursing home facilities; and to do so in a manner which will not increase overall costs to the Medicaid program. In order to encourage dementia-friendly facility design, DHS will increase the weight of dementia-capable design criteria in its project approval process.

Projects approved by the Nursing Home Modernization Program will forecast cost neutrality to the Medicaid program, given assumptions regarding the amount of incentive to be received and the number of Medicaid patient days to be billed to the state. Resident-centered design elements that have a clear focus on improving care outcomes for residents with behavioral and cognitive impairment challenges, including

dementia-related needs, will significantly enhance the likelihood of project approval. In order to expand the dementia-friendly facility design projects beyond those that could be achieved under the current program parameters, DHS will explore the possibility of relaxing the cost neutrality requirement for approved dementia friendly design projects. This approach would require identifying additional sources of funding to cover associated costs.



5.3 Care for People with Significant Challenging Behaviors

Care for people with dementia can be difficult, especially when the person becomes self-injurious, aggressive or violent towards others. These kinds of behavior occur in a small proportion of people with Alzheimer's disease or related dementias; however, these behaviors demand attention because of the immediacy and intensity of the need. The difficulty of dealing with the situation increases when these episodes are frequent and long term. Other behaviors such as wandering, entering other residents' rooms uninvited, repetitive questioning, sexual inappropriateness, refusal to bathe or accept care, and the need for constant supervision can also be challenging to care providers.

Challenging behaviors are often a way for persons with dementia to communicate once they are unable to verbalize their needs. For example, a woman who does not recognize the caregiver who is trying to help her undress in order to take a shower may perceive the situation as an assault and strike out to protect herself. Challenging behaviors exhibited by persons with dementia can occur in the context of interactions between the individual and his or her environment and caregivers. Contributing factors may include untreated pain, an underlying medical condition, medication side effects, noise, light, behavior of other facility residents, a move or a change in the physical environment. A caregiver's response can either ameliorate or exacerbate the challenging behavior of the person receiving care.

Responding to challenging behaviors by removing an individual with dementia from his or her current living environment to an alternate setting can further exacerbate confusion and agitation, and may cause unnecessary stress and produce negative health outcomes for the person. The goal is always to respond to the challenging behaviors in a manner that causes the least possible disruption to the person.

Although a person may have both dementia and a mental illness or substance use disorder, for an individual with dementia only, the appropriate response to challenging behaviors is likely to be different from the response needed in the case of challenging behaviors among people with mental illness and substance use disorders. Currently, there are no generally accepted standards that can be used to appropriately and adequately evaluate the type and level of care needed by people with dementia who exhibit challenging behaviors.

5.3.1 Expand Capacity for Crisis Response and Stabilization

Counties are required to provide emergency mental health services under Chapter 51 of the Wisconsin Statutes and DHS 34 of the Wisconsin Administrative Code. Crisis response and stabilization services deal with challenging situations or behaviors. However, many county crisis intervention teams do not have specific training to identify and manage people with dementia. This strategy gives crisis intervention programs the tools they need to better identify, evaluate, and provide crisis response plans for people with dementia who exhibit violent, aggressive, or other serious challenging behaviors.

Related Strategies

- **Develop and disseminate dementia assessment tools for use by crisis response and stabilization teams.**

Crisis response teams need to be more capable in identifying and evaluating people with dementia who are exhibiting challenging behaviors. In order to appropriately intervene, this strategy will develop and disseminate assessment tools for crisis intervention programs to use when intervening with a person who is thought to have Alzheimer's disease or a related dementia. These tools, to be developed in coordination with experts and stakeholders, will be culturally competent and include, at a minimum, dementia symptoms; associated medical, psychiatric, and substance abuse issues; the person's environment; and the caregiver(s) response to challenging behaviors.

- **Promote dementia-capability in the existing mobile crisis response system.**

County crisis intervention programs provide services to people with a range of diagnoses and conditions, including people with mental health and substance use disorders, as well as people with dementia. Crisis intervention programs need to be dementia-capable to meet the need of this distinct population.

Crisis response systems in Wisconsin vary from county to county, depending on local practices and available resources. In many areas, crisis intervention programs exist but are not fully dementia capable. In other areas, there is no effective crisis response beyond calling 911 or the sheriff's department. Some counties have developed highly skilled mobile crisis intervention services.

Mobile crisis intervention services are designed to assess and treat people in place, whether in the person's home or in a facility setting, thus minimizing the need to hospitalize or relocate the person to an unfamiliar, more intensive and costly service setting. Dementia-capable mobile crisis response is, therefore, the preferred approach for intervention with a person with dementia exhibiting significant challenging behaviors.

This strategy involves:

- Reviewing current mobile crisis intervention programs to identify common features of successful models when addressing challenging behaviors related to dementia and provide examples of effective partnerships with Adult Protective Services, law enforcement, first responders, emergency medical staff, managed care organizations, the local corporation counsel and court system, district attorneys, and other agencies that may be involved. The review will include identifying barriers to success and developing ways to overcome obstacles.
- Developing and pilot testing a model for a dementia-capable mobile crisis intervention focused on treating people in place. The model will identify the

various stakeholders whose participation will be needed, including MCOs, clarify their respective roles and responsibilities, provide sample memorandums of understanding (MOUs) or other documents for use in replicating the model, and achieve a more consistent application statewide.

- Pilot testing this model in one or more areas where mobile crisis intervention service is not currently viewed as “dementia capable.” Service utilization and outcomes will be analyzed to evaluate the success of the approach.
 - Building on the strengths and learning from the challenges identified in the pilots to support expansion of dementia capable mobile crisis response services.
- **Explore amending DHS 34 to expand mobile crisis response programs to ensure dementia-capable capacity.**

Mobile crisis response is provided by county crisis intervention programs certified under DHS 34 Subchapter III of the Wisconsin Administrative Code. Sixty-one of Wisconsin’s 72 counties currently have service under a Subchapter III certified crisis program. These crisis programs are required to have a mobile component and are eligible for Medicaid, and in some cases, other insurance reimbursement.

Crisis intervention programs certified under DHS 34 Subchapter III are required to make the following services available 24 hours a day, seven days a week: crisis telephone hotline, short-term voluntary or involuntary hospital care, and linkage to and coordination of services. Additionally, Subchapter III programs are required to have mobile crisis services available eight hours per day, seven days a week, at times when services are most needed and to offer walk-in services eight hours a day, five days a week.

This strategy calls for moving toward dementia capable, 24-hours/7 days a week mobile services through crisis intervention programs and statewide coverage under DHS 34 Subchapter III programs. This includes providing dementia-specific training to crisis teams and exploring funding options to support this level of available response.

5.3.2 Clarify Procedures for Emergency Protective Placement

The requirements under Chapter 55 of the Wisconsin Statutes related to procedures for emergency protective placement of persons with dementia need to be clarified and implemented in a consistent manner across the State. The emergency protective placement law does not explicitly address a number of issues that arise when placements are made and county APS agencies, county corporation counsel, crisis units, law enforcement, and facilities often interpret the law differently. This leads to inconsistencies among counties and less than optimal care for people with dementias who are the subject of emergency protective placement. Of particular concern are practices used to transport individuals who are subject to emergency

protective placement. People with dementia suffer trauma when handcuffed by law enforcement and transported in squad cars.

Related Strategies

- **Identify areas that need clarification related to emergency protective placement requirements and procedures.**

Even if a facility is willing to accept emergency protective placements as a general rule, there are obstacles that preclude acceptance in particular cases. One frequently mentioned obstacle is the lack of a surrogate decision-maker to authorize treatment at the time the placement is made. When the individual cannot be managed without authorized treatment during the 72-hour period before a probable cause hearing is held and no surrogate decision maker has been named, facilities will decline to accept the emergency protective placement.

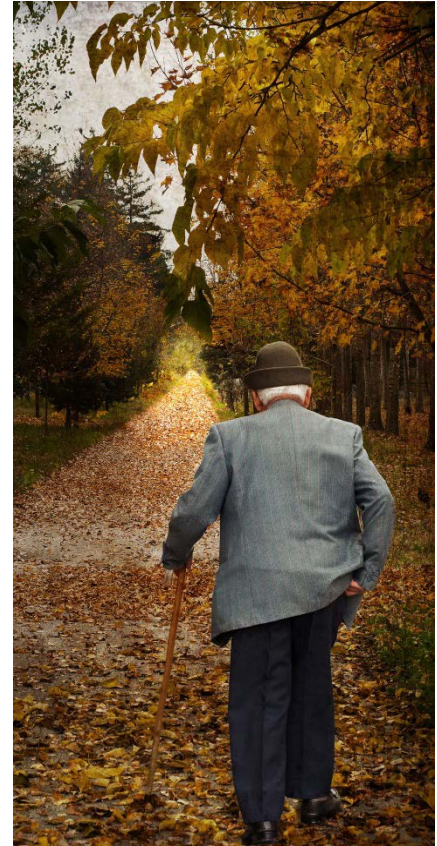
Other obstacles include regulatory requirements for medical evaluations, physician's orders, and communicable disease clearance prior to placement in a nursing home or assisted living facility. Another concern occurs when a facility accepts an emergency protective placement and realizes later it is unable to manage the person's challenging behaviors. This strategy involves:

- Conducting a review of the statutes and regulations governing protective placement and facility admissions and administering a survey of stakeholders to identify concerns related to real or perceived obstacles to emergency protective placements for people with Alzheimer's disease and related dementias. This will be done in consultation with the Department of Justice and other stakeholders.
- Provide facilities, and other participants in the emergency protective placement process, with clear guidance related to emergency protective placements in different types of settings and propose statutory or rule changes to address the identified obstacles to a smooth emergency protective placement process.

5.3.3 Address the Shortage of Facilities Designated to Accept Emergency Protective Placements

By law, counties are required to designate at least one intake facility for emergency protective placements. Based on a survey conducted by the Department's Office on Aging in 2011, it is estimated that fewer than 15 of Wisconsin's 72 counties have formally designated intake facilities for this purpose. A handful of other counties have informal arrangements with facilities to accept placements based upon bed availability and the facility's capacity to manage the particular challenging behavior.

Many facilities will not accept emergency protective placements involving persons with dementia because caring for them can be difficult, the facility is unequipped to meet their needs, or they fear sanctions from the licensing authority for the person's behaviors that place other residents in jeopardy. Facilities are especially concerned about the obligations and liability associated with aggressive or violent behaviors that are difficult to manage. This strategy aims to increase the availability of designated emergency protective placement facilities by identifying and addressing the obstacles to intake facility designation.



Related Strategies

- **Identify obstacles to designation of emergency protective placement facilities.**

The Department will survey facilities that have accepted emergency protective placement designation, as well as facilities that have not accepted placements, to identify factors that either facilitate or present barriers to designation as a protective placement facility. This will assure accurate data to better understand the system's current capacity and limitations.

- **Create consistent standards and training related to crisis and caring for persons with challenging behaviors.**

The Department will develop standards and accessible training opportunities related to crisis and caring for persons with challenging behaviors. These efforts are expected to enhance facilities' abilities to serve as emergency protective placement facilities. This strategy is described under section 5.4, "Dementia Care Standards and Training."

- **Identify and pursue options to address facility concerns and incentivize facility designation.**

The Department will work with stakeholders to identify actions that may be taken to address their concerns, or provide them with an incentive for accepting designation and admitting people with challenging behaviors for emergency protective placement. Potential incentives to be considered include provision of specialized training, mentorship from successfully designated facilities, and reimbursement rates sufficient to cover the cost of increased staffing levels, when necessary. Other options to consider include designation of facilities that specialize in providing care for behaviors of particular types and acuity levels and designation of regional facilities to serve smaller and more rural counties.

- **Explore the need for specialized facilities for placement of those few people who present extremely aggressive and violent behaviors and/or have longer term care needs related to challenging behaviors.**

There are a number of Wisconsin facilities capable of providing the specialized care that individuals exhibiting extreme or on-going challenging behaviors require. Exemplary facilities will be identified in consultation with stakeholders, and model standards and best practices will be developed based on their experience, together with a review of the professional literature. The models will be disseminated and training provided to facilitate their replication in other facilities. The approaches which these facilities have implemented can be examined, translated into standards or best practice guidelines, and replicated in other facilities willing to care for these individuals. County and Department staff will work to identify and recruit facilities which are willing to assume responsibility for caring for this population on a long term basis. Regional facilities of this type will be considered. Technical assistance and support (e.g., mentor program, training) will be provided to these facilities and their implementation of specialized services will be monitored.

5.4 Dementia Care Standards and Training

In order to have a dementia-capable system of care, there must be a widely shared understanding of what constitutes appropriate and high quality care for people with dementia, as well as providers who subscribe to that shared vision and a competent and well-trained workforce in place to provide the care. Standards will articulate, document and share a common understanding of these values. Guidelines, best and promising practices, and training opportunities related to dementia care are available from a variety of sources. While there may be multiple sets and sources of standards, it is important that all partners in Wisconsin's system be operating under the same or compatible standards and guidelines. This effort will build on and supplement, but not replace, existing programs and practices. An ongoing and sustainable program for implementing the standards through training and other means will also be needed to achieve the vision of a dementia-capable system of care for Wisconsin.

5.4.1 Catalog and Publicize Existing Dementia Care Training Programs

A variety of training opportunities already exist for family caregivers, facility staff, and others who care for and interact with people with dementia. For example, training and education on dementia care is currently provided by the Alzheimer's Association and the Alzheimer's and Dementia Alliance of Wisconsin, the state's four major nursing home and assisted living trade associations, vocational and technical colleges, and individual facilities and programs.

Related Strategies

- **Identify existing dementia care programs.**
The Department will survey stakeholders to compile a comprehensive list of available dementia education and dementia care training opportunities in Wisconsin.
- **List training opportunities on the Department's expanded dementia care website.**
The list of training opportunities will be posted on the Department's dementia care website, together with brief descriptions of the intended audience, content, cost, availability, and links to contact and other information about the sponsoring organization. A process will also be developed for updating the information to ensure its continued accuracy and relevance. The Department will publicize the availability of the training and the website through its communications with licensed providers and the Aging and Disability Resource Centers and Managed Care Organizations.



5.4.2 Develop Dementia Care Standards for Caregivers, Providers and Other Professionals

The dementia care system involves many different groups, including caregivers, clinicians, law enforcement and other professionals, home care agencies and other service providers, and care facilities. Standards are needed both for caregivers and other professionals who have the direct, in-person contact with people with dementia and for the provider agencies and facilities where the care takes place. Guidelines will need to be tailored to the roles the different stakeholders play in the system. And a process for periodically evaluating, revising and redeploying the standards will be developed to assure that Wisconsin remains a leader in Alzheimer's and dementia care.

The Department is pursuing an interagency agreement between the Department and the UW-Oshkosh Center for Career Development and Employability Training (CCDET) to develop standards. Facility and service providers, clinical professionals, advocates and other stakeholders will be closely involved, along with Department staff, at all stages in the standards development process. Final standards will be subject to approval by the Department of Health Services.

Related Strategies

- **Research existing standards and best and promising practices.**
Current policies, guidelines and best practices will be reviewed to provide a foundation for Wisconsin's standards development effort. The Alzheimer's Association, the National Institute on Aging's Alzheimer's Disease Education and Referral Center, other academic research, provider trade associations, consumer advocacy organizations, and regulatory and funding agencies in other states will be among the various resources examined.
- **Develop voluntary training standards for caregivers and other professionals involved with people with dementia.**
While a number of training opportunities are available, there is currently no consistent set of standards for determining what knowledge, competencies and training are needed for caregivers and other professionals who work with people with dementia. This strategy develops a foundation for the entire spectrum of training opportunities, taking into account the training resources that are currently available and supplementing those with widely accessible and affordable training resources.

Standards will be developed for a variety of audiences, including homecare workers, facility and other service provider staff, law enforcement, judges, crisis workers, hospital emergency room and other medical professionals, and county or MCO staff. The definition of challenging behaviors to be used across all groups will be developed to ensure a common understanding of the term. The standards will contain a set of basic core competencies, together with specialized components for the different audiences based on the roles of the professionals involved. These standards will be culturally

competent and cover a variety of topics, such as risk and protective factors, early detection, assessment, care planning, principles of person-centered care, promoting independence and maintaining function, recognition and management of challenging behaviors, palliative and end-of-life care. Once developed and agreed to, the standards will be made available to all through the Department's website.

- **Develop Dementia Care Standards and a Voluntary Assurance Program for Facilities and Home Care Agencies.**

There is no consistent set of standards by which to determine needed services or to evaluate the quality of care that is available for people with dementia. People with Alzheimer's disease and related dementias have varying levels of acuity and care needs and facilities provide different types and levels of care. Wisconsin has neither general standards concerning what constitutes appropriate care for people with dementia nor specific standards based on the level of care provided by the facility and the acuity of the people it serves. As a result, the nature and quality of dementia care services vary widely. In addition, people seeking services lack reliable ways of assessing either the appropriateness or the quality of the services being offered. This strategy will involve:

- ***Determining standards for facilities and providers.*** Standards will be tailored to the different facility and provider types, the nature and level of dementia care provided, and the range of acuity levels served by each particular provider type. Separate standards may be considered for facilities and programs serving a general population that includes people with dementia, facilities or units presenting themselves as providing a dementia care program, and specialty programs designed for people who exhibit the most challenging behaviors. All care standards will incorporate the principles of cultural competency. The categories of standards to be developed will be identified based on a review of national standards for dementia care, the experience of other states, standards that have been developed and adopted by provider trade associations, along with input from Wisconsin stakeholders.
- ***Developing standards based on the type of provider or facility, the type and level of dementia care provided, and the acuity of the people served.*** Standards will be developed for facilities and service providers that contain expectations for staff training consistent with the caregiver standards described above, together with additional standards relating to the level of care provided by the facility and the acuity of the people they serve. Possible topics for inclusion in the standards include: the dementia-specific services to be provided, staff qualifications and training, staffing ratios, design of the physical environment, procedures for handling challenging behaviors; and criteria for admission, transfer and discharge. Standards will be publicized on the Department's dementia web page and through communications with providers, MCOs and ADRCs.

- ***Creating and implementing a process for providers to attest to their compliance with applicable dementia care standards.*** DHS will promote voluntary use of the provider standards, including guidance on worker training, and develop a system in which facilities can attest to their adherence to the dementia care standards. This information on facility assurances will be made available to consumers, together with information on additional resources for consumers. Consumer information will include: considerations for selecting a care facility, the facility’s performance related to rating systems, and inspection survey results.
- ***Disseminating information regarding the standards and assurance process.*** Information about the provider standards and related training opportunities will be made widely available to all interested parties. The Department will provide information on the standards to nursing homes, assisted living facilities and home health agencies through its normal notification process on the web; promote their use through communications with industry trade associations, MCOS, ADRCs and other long term care programs and agencies; and provide information to consumers through advocacy organizations and consumer-oriented pages on the Department’s website.

5.4.3 Provide Additional Training Opportunities Relating to Dementia Care

A well-trained, competent workforce is critical to the provision of quality dementia care. The development of additional dementia training opportunities that can be made widely available statewide at an affordable cost is a key aspect of this strategy. The Department will sponsor development of a training and certificate program based on the standards that are developed as part of this dementia care initiative. Caregivers and others who successfully complete the training program will be awarded a certificate of completion and be able to place their names on a registry of trained personnel.

The training curriculum, competency testing, registry and certificate process will be developed through an inter-agency agreement between the Department and the UW-Oshkosh Center for Career Development and Employability Training (CCDET). Current training opportunities will be taken into account, stakeholders will be involved in the development of the training curriculum, and the resulting products will be subject to Department approval.

The training and certificate program will be evaluated and revised periodically to assure that Wisconsin remains a leader in Alzheimer’s and dementia care.

Related Strategies

- **Develop a training program for caregivers and other professionals.**
The training program will include both general training and specialized training modules for staff working in long term care settings or serving in other specific professional roles such as law enforcement. The training will be primarily web-based, supplemented by

classroom training with an experiential component for more complex issues relating to management of challenging behaviors, to assure statewide accessibility and sustainability. Activities related to this strategy will include development and production of:

- Training curricula, including general training, training for staff in long-term care settings, challenging behavior specialist training, and crisis response intervention training.
 - Online training modules.
 - Classroom and experiential components for training relating to challenging behaviors.
 - Participant handbooks and resource materials.
- **Develop a competency testing and certificate program.**
People who complete one or more of the training modules will be able to take a competency test and, upon achieving a passing grade, will be awarded a certificate of completion for that portion of the training program.
 - **Create a registry of trained caregivers and professionals.**
People who have completed the training program and received a certificate will be listed in an on-line registry. The registry will be available to prospective employers and people looking for facility or home care services.

5.4.4 Create Incentives for Compliance with Staff Training and Other Standards

Agency and provider compliance with staff training and provider standards will be voluntary. The intent is that facility, and other service provider participation, will be motivated by the desire to provide quality care and to be competitive with other providers. The Department will explore other incentives that could be used to further encourage compliance.

Related Strategies

- **Promote voluntary use of dementia care standards and training programs.**
Voluntary use of standards and training will be encouraged in a variety of ways, including:
 - Providing information about the standards and training opportunities to the provider community.
 - Providing an opportunity for facilities and other providers to “brand” their services as dementia-capable by creating a registry of those that attest to their compliance with the dementia care standards.
 - Creating a caregiver registry for those who have successfully completed an approved dementia care training program and earned a certificate.

- Letting consumers know to look for and ask about whether the home care services or care facilities they are considering have trained staff and comply with the dementia care standards.
- **Encourage MCOs to contract with providers that follow the dementia care standards.**
The Department will work with Family Care MCOs to ensure that Family Care members with dementia receive dementia-capable care consistent with the standards that have been developed for caregiver training and providers. MCOs will also be encouraged to include provider contract requirements to comply with state-approved dementia care standards, including staff that have completed and obtained certificates of training.
- **Explore financial incentives for providers that comply with staff training and other dementia care standards.**
The Department recognizes that quality care for people with dementia and meeting these standards involves additional staffing and other costs. The Department will evaluate these costs with regard to reimbursement and rate-setting methods. This will involve:
 - Identifying possible financial incentives for high quality dementia care through the Medicaid fee-for-service (FFS) rate setting methodology for nursing home reimbursement. One possibility would be to expand the current Medicaid incentive for nursing homes providing care for residents with behavioral and cognitive impairment challenges.
 - Encouraging MCOs to build dementia care expectations and incentives into their contracts with the nursing homes, assisted living facilities and community-based providers in the MCO's provider networks.

5.5 Research and Data Collection

Information about the prevalence of dementia, circumstances of individuals with dementia, service capacity and utilization, as well as the cost and quality of dementia care, is critical to the implementation of the strategies that have been identified for promoting a more dementia-capable system of care in Wisconsin. The Department's ability to measure success as system improvements are made is essential. Therefore, existing information sources will need to be revised and updated, and new sources of information developed in order to inform the continued development and implementation of the strategies for achieving a dementia-capable system of care as described in this report.

5.5.1 Develop and Implement a Data Collection Plan to Facilitate Quality Measurement Related to Dementia Care

A number of data sources are available that would provide a factual basis for projecting the demand for services, understanding costs, developing incentives, and measuring quality of care and the impact of implementing the various strategies outlined in this document. Currently available and supplemental data sources will be evaluated to identify information elements, integrate data flow, standardize data processing, and make the needed data available in a timely and accurate manner.

Related Strategies

- **Identify data elements and sources for developing baseline measures.**
Existing data sources include Medicaid eligibility and enrollment information, Long Term Care Functional Screen data, long term care encounter data for the Family Care program, Medicaid fee-for-service claims, and MDS information for nursing home residents, the Behavioral Risk Factor Surveillance System, information on facility capacity, regulatory violations and enforcement, and more. Additional information sources may be tapped through partnerships with academic research organizations (e.g., CHSRA, CAARN), health systems, MCOs, trade associations, counties and others who share an interest or have a stake in the success of the dementia care initiative. Current data and potential supplemental data sources will be reviewed and evaluated to determine information sources that will inform and evaluate these efforts.
- **Develop and employ metrics for measuring progress in achieving a dementia-capable system of care.**
Performance indicators will be developed and key benchmarks established to use in measuring progress in achieving Wisconsin's dementia-capable vision and goals. Stakeholders will be consulted in the development of these indicators.
- **Collect and analyze data to determine baseline and quality improvement.**
The Department will collect and analyze data to inform further development of the dementia initiative, evaluate the capacity and quality of Wisconsin's dementia care system, and measure the progress made in achieving a more dementia-capable system of care.

5.5.2 Inventory Providers of Dementia Care

Information about dementia care providers is needed in order to assess the adequacy of Wisconsin's current system and to identify needed capacity and service improvements. The Department collects information about and maintains directories listing the providers it regulates, including nursing homes, CBRFs, RCACs, adult family homes, adult day care, and home health agencies. Information on the licensing category, number of facilities, licensed capacity such as the number of beds or units, and regulatory history is available for all provider

types. The amount and type of additional information available varies by licensing category. Detailed information about nursing home residents, including residents with dementia, is captured in the federally required MDS. Assisted living facilities self-identify the populations they are licensed to serve, including individuals with dementia, and this information is included in the provider directories. However, information about the nature and amount of dementia-specific services available in nursing homes, assisted living facilities, home health agencies and other care providers is not currently available.

Related Strategies

- **Develop provider classifications relating to the dementia care services provided and acuity of the population served.**

People with dementia require different levels of care as their disease progresses, and people respond to the disease in unique ways. Differences in acuity levels and care needs should be taken into account when placing or moving people with dementia from one care setting to another. Currently, it can be difficult to identify appropriate settings for people based on their dementia care needs, as no inventory exists of facilities based on the level of care they provide. A stakeholder workgroup will be convened to assist the Department in developing a classification system that can be related to service standards and caregiver training needs. A classification system could differentiate those providers or facilities delivering a basic level of care from those that are equipped to provide crisis stabilization and response, address co-occurring medical or psychiatric conditions, or manage challenging behaviors on a long-term basis.

- **Conduct a statewide inventory of dementia care facilities and services based on the level of dementia care they provide.**

The Department will develop an instrument for collecting relevant information from MCOs, counties, tribes, facilities and community dementia care providers, and other stakeholders. Questions to be addressed in the survey could include such things as:

- Do staff have dementia-related training?
- Are dementia-specific services provided?
- Do facilities have protocols to identify challenging behaviors? Do those protocols vary based on acuity?
- Can the facility describe their admission and discharge policies related to cognitive status and behavior?
- Does the facility have an accepted designation as an emergency protective placement facility, and what is its capacity to handle these situations?
- Can the facility describe the procedures and arrangements they have with counties for emergency protective placements?

Data will be compiled into a resource inventory to describe and quantify the resources available to provide dementia care at the different levels of acuity reflected in the proposed classification system.

- **Analyze data to evaluate the availability of dementia-capable care appropriate for different acuity levels across the state.**

Survey results will allow the Department to identify gaps in the geographic availability of care for people at different levels of acuity, determine whether there is a need for regionally-based facilities, as well as potential locations of such facilities, and evaluate the extent to which providers engage in dementia-capable practices across the spectrum of care.

Provide consumers with information about dementia care providers. Inventories of dementia care providers, including information about their classification, level of care provided and geographic availability, will be made available to consumers to assist them in locating and making decisions about care providers. The information will be made available in a format that is easily accessed and navigated.

5.5.3 Analyze Cost Implications of the Strategies in the Plan

The Department will analyze the fiscal impact of the strategies in the Plan to determine whether the necessary resources are available. Both short- and long-term funding needs will be assessed in order to ensure that successful systems improvements can be maintained over time.



6.0 Next Steps: Moving Forward with the Agenda

6.1 We Are All in This Together: Partners and Stakeholders

The agenda set forth in this document focuses on actions the Wisconsin Department of Health Services will take to promote development of a more dementia-capable system of care in Wisconsin. Successful implementation of the strategies in the Plan will only be possible by working closely the Department's many partners involved in providing dementia care services. With the completion of this revised Plan, the next step for the Department is to mobilize the internal teams that will ensure the Plan moves full steam ahead. Each of these teams will be charged with creating a method to engage stakeholders, including those who expressed their willingness to help when they responded to the Stakeholder Survey released with the draft Plan.

In addition, the Department is creating a webpage on the Dementia Care System Redesign which will be used to provide stakeholders with updates on implementation progress. This page can be found on the "Department of Health Services Priority Initiatives" section of the home page of the Department's

website: <http://www.dhs.wisconsin.gov/aboutDHS/initiatives/dementia/>.

This page will also host information on continued opportunities for involvement as the work of implementing these strategies proceeds.

6.2 Key Milestones and Target Dates

Secretary Kitty Rhoades has committed the Department of Health Services to moving forward quickly in redesigning the system of dementia care in Wisconsin. The goal is create the foundation for a "Dementia-Capable Wisconsin" by the end of the 2013-15 biennium. A table showing "Implementation Targets and Milestones" has been included as an appendix.

With the release of the Department's revised System Redesign Plan, there will be continued opportunities for involvement as the work of adding detail to and implementing these strategies is undertaken. The Department looks forward to working with you as it strives to improve the system of care and support and to provide the highest quality of life possible for people with dementia throughout the State of Wisconsin.



7.0 Appendices

7.1 Appendix A: Comparison of Proposed Strategies to Summit Priorities

The launch of this effort to redesign the system of dementia care in Wisconsin began with the Department of Health Services seeking the advice of key experts and stakeholders through a Dementia Care Stakeholder Summit. Summit participants identified six top priorities, which became the focal point for developing the strategies included in this draft Plan. A table that highlights the Stakeholder Summit priorities and the link to the System Redesign strategies in this plan is provided in Appendix A. The full Summit report can be found at <http://www.dhs.wisconsin.gov/publications/P0/P00563.pdf>

7.2 Appendix B: Implementation Milestones and Timelines

A table showing the “Implementation Milestones and Timelines” is provided in Appendix B.

7.3 Appendix C: Stakeholder Survey Report

The Department’s Dementia Care System Redesign Plan was initially released as a draft to provide partners throughout the dementia care network with an opportunity to provide their thoughts. Stakeholder feedback was collected through a web-based survey linked to the draft plan. In addition, some individuals and organizations submitted comments directly to Department leaders. Responses were analyzed and considered in creating this revised Plan. A summary of the stakeholder input, along with a description of the process for reviewing and incorporating stakeholder input into the Plan itself, is included in Appendix C. A comprehensive list of the open-ended comments received from survey respondents can be found at: <http://www.dhs.wisconsin.gov/publications/P0/P00603.pdf>.

Appendix A

Comparison of Proposed Strategies to Summit Priorities

Stakeholder Summit Priority	System Redesign Strategies for Addressing Summit Priorities: Some Highlights
<ul style="list-style-type: none"> Increase community awareness of dementia issues and of the resources available to provide support to people with dementia and their family caregivers. 	<ul style="list-style-type: none"> Updates resource information available through ADRCs and the DHS website. Expand access to dementia screening. Expand evidence-based programs for people with early stage dementia. Expand access to education and support for family caregivers.
<ul style="list-style-type: none"> Expand the use of dementia care specialists and case managers to coordinate care, help with transitions, and work with people and their families throughout the disease process. 	<ul style="list-style-type: none"> Adds 10 dementia care specialist in ADRCs in 2014 and expand the program statewide as resources are identified.
<ul style="list-style-type: none"> Revise state regulations to allow for “safe harbors” that let facilities care for challenging residents in place with less fear of liability or regulatory penalties. 	<ul style="list-style-type: none"> Analyze and educate providers about factors leading to immediate jeopardy citations and how to avoid these situations. Seek federal regulatory flexibility for the state in applying immediate jeopardy citations to facilities that follow best practice guidelines.
<ul style="list-style-type: none"> Create fiscal and systemic incentives for best practices. 	<ul style="list-style-type: none"> Disseminate information related to promising dementia care practices. Review the rate setting methodologies and MCO contracting practices. Create incentives for dementia-friendly facility design. Develop voluntary standards for caregivers and facilities. Provide training and certificate programs for providers and facilities. Create a registry of trained caregivers and identify facilities that provide an assurance of compliance with quality standards.
<ul style="list-style-type: none"> Expand mobile crisis teams to assess and diffuse difficult situations and help avoid the need for more restrictive placement. 	<ul style="list-style-type: none"> Develop and pilot a model for dementia-capable mobile crisis response teams. Propose revisions to DHS 34, or clarify through rules and policy, the need for mobile crisis with 24/7 availability.
<ul style="list-style-type: none"> Create placement facility capacity to care for people with complex and challenging behavior needs. 	<ul style="list-style-type: none"> Clarify procedures for emergency protective placements. Identify and pursue options to address facility concerns and provide incentives for designation as an emergency protective placement facility.

Appendix B

Implementation Milestones and Timelines

The following table lists key steps in implementing the strategies in the dementia agenda, together with dates by when the majority of the work will be initiated.

Community Awareness and Services	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	2015- 2017 Biennium
Increase Understanding and Awareness of Dementia				
<i>Expand the Dementia Care Specialist (DCS) Program in ADRCs.</i>				
1. Select additional 10 ADRCs to begin DCS.	X			
2. Expand DCS program statewide.				X
<i>Facilitate access to dementia care resources in the community through outreach, information and referral; web-based resources.</i>				
1. Assure that Dementia resources in ADRC databases are updated.	X			
2. Improve the DHS dementia care webpage.		X		
3. Encourage ADRCs to outreach to community agencies and organizations to increase referrals.	X			
<i>Increase the capability and capacity of MCOs in providing dementia care services.</i>				
1. Designate dementia care leads in each MCO.	X			
2. Ensure that MCOs to work with provider networks to develop skills needed to manage challenging behaviors and prevent crises.		X		
3. Develop and test enhancements to the LTC functional screen regarding behavioral care needs.	X			
4. Work with MCOs to develop best practice guidelines	X			
<i>Promote dementia-friendly communities.</i>				
1. Work with Wisconsin communities to develop a “dementia-friendly community” toolkit.		X		
2. Educate people about dementia-friendly communities at DHS-sponsored conferences and other public events.	X			
3. Coordinate the Department’s message with community partners.	X			
4. Partner with private and public employers to support dementia-capable work environments.	X			
<i>Engage the medical community in the dementia initiative.</i>				
1. Partner with agencies such as the Wisconsin Medical Society and the Wisconsin Hospitals Association.	X			
<i>Engage public health departments in the dementia initiative.</i>				
1. Evaluate option for inclusion of dementia care in the state health plan.	X			
2. Promote the Department’s view of dementia as a public health issue to local public health departments.	X			

Community Awareness and Services	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	2015- 2017 Biennium
<i>Promote the use of the Department of Public Instruction dementia curriculum.</i>				
1. Partner with DPI in encouraging the use of the curriculum in middle and high school health classes.	X	X	X	
<i>Ensure community based dementia services are culturally competent.</i>				
1. Ensure the principles of cultural competency are incorporated into system and program development and service provision	X	X	X	
Facilitate Early Identification and Intervention				
<i>Expand capacity for dementia screening and diagnosis.</i>				
1. Develop a system for ongoing training and oversight of cognitive screening at ADRCs and MCOs.	X			
2. Partner with Wisconsin Alzheimer’s Institute to enhance physician awareness and encourage collaboration with the screening process.		X		
3. Work with existing community organizations to document, describe, and expand the available programs.	X			
4. Assure that early stage dementia program options are disseminated by all ADRCs and MCOs.	X			
<i>Provide early stage programs and supports.</i>				
1. Coordinate with dementia specialists to identify and describe best practices among dementia support programs.	X			
2. Promote evidence-based dementia support programs throughout the state (e.g., Memory Care Connections, Savvy Caregiver, LEEPS, and “Powerful Tools for Caregivers” [PTC] leader training; [goal of at least one PTC class location in each county by 2015]).	X		X	
Provide Support for Family Caregivers				
<i>Expand access to caregiver education and support program.</i>				
1. Promote community outreach activities that help family caregivers identify themselves as a critical component of the dementia care system.	X			
2. Expand partnerships with health care and community organizations to fund or provide caregiver support programming.	X			
<i>Expand and update Alzheimer’s Family Caregiver Support Program (AFCSP).</i>				
1. Update program parameters for changes in eligibility and cost of care standards.	X			
2. Work with aging units and ADRCs to increase AFCSP and NFCSP awareness through community outreach and marketing.	X			
3. Develop strategies to increase funding for AFCSP.	X			
4. Consult with tribes to determine unmet needs in tribal communities and establish a 2015 AFCSP allocation.		X		
<i>Promote dementia care volunteer programs.</i>				
1. Develop a toolkit for replication of dementia care best practices for volunteers.			X	
2. Provide grant funding to create dementia volunteer coordinator positions.				X

Facility-Based Long Term Care (Nursing Facilities, Adult Family Homes, Community-Based Residential Facilities, Residential Care Apartment Complexes and Adult Family Homes)	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
Address Barriers That Prevent Facilities From Admitting Residents with Challenging Behaviors				
<i>Identify factors leading to citations related to challenging behaviors and educate providers on strategies to prevent these events.</i>				
1. Conduct a comprehensive study of all findings of immediate jeopardy citations that relate to residents with behavioral symptoms. Conduct a similar study of serious violations issued against assisted living facilities related to residents with behavioral symptoms.	X			
2. Identify the specific deficient practice and conduct a root cause analysis of each problem.	X			
3. Identify common care omissions that result in findings of immediate jeopardy.	X			
<i>Develop guidelines to address the causes of citations.</i>				
1. Develop comprehensive best-practice guidelines that emphasize consistent staff assignments, staff training, and assessment for underlying causes of behaviors (e.g., pain, physical illness, or boredom) in order to effectively care for residents with behaviors that threaten other residents.	X			
2. Develop a decision tree for facilities to show the necessary components of a good dementia care system to include problem identification, assessment of the behavior, development of a multi-disciplinary care plan, data collection to evaluate the effectiveness of the plan, and the use of new interventions as needed.	X			
<i>Seek federal flexibility for nursing home providers who follow guidelines.</i>				
1. Share Wisconsin's Best Practices and Decision Tree for providing care for residents with behavioral symptoms with CMS.		X		
2. Seek CMS flexibility for providers that use Wisconsin's Best Practices and Decision Tree. Emphasize that Wisconsin does not seek a lesser standard for facilities but recognizes that not all behaviors are predictable and preventable.		X		
Continue to Improve the Quality of Dementia Care in Facility Settings				
<i>Provide staff training opportunities.</i>				
1. Encourage facilities to share information about and utilize existing training opportunities. Develop and hold regular regional workshops designed to promote the use of best practices developed by facilities and DHS.		X		
2. Develop a comprehensive dementia care training curriculum, with components tailored to different types of caregivers and providers, and make the training widely available to facilities		X		

Facility-Based Long Term Care (Nursing Facilities, Adult Family Homes, Community-Based Residential Facilities, Residential Care Apartment Complexes and Adult Family Homes)	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
and other providers.				
<i>Disseminate information on promising dementia care practices.</i>				
1. Encourage facilities to submit information about successful programs they have developed to the Resource Center and Coalition so that they can be shared with others.	X			
2. Hold regional workshops for facilities, provider associations, Department staff and other stakeholders to share best practices. Publish the results of the workshops on the Resource Center and Coalition webpages.		X		
3. Provide technical assistance and mentorship opportunities to facility staff.		X		
<i>Explore incentives for facilities that adopt best or promising practices and show positive outcomes.</i>				
1. Identify possible financial incentives for high quality dementia care through the Medicaid fee-for-service rate setting methodology.			X	
2. Encourage MCOs to build dementia care expectations into their contracts with the nursing homes and assisted living facilities in their provider networks.	X Info sharing		X Funding change	
<i>Promote adoption of voluntary standards for dementia care.</i>				
1. Develop voluntary standards for facility-based dementia care as part of a more comprehensive standard and training initiative.		X		
Promote Dementia-Friendly Facility Design				
<i>Encourage facilities to adopt design elements known to support dementia care.</i>				
1. Work with stakeholders to identify elements of a dementia friendly environment and disseminate the information through regional dementia care workshops and publish on the Resource Center, Coalition and DHS websites.	X			
<i>Provide financial incentives to encourage facilities to undertake dementia-capable design projects.</i>				
1. Increase the weight of dementia-capable design criteria in the Nursing Home Modernization Program approval process to encourage facilities to undertake dementia-capable design projects.	X			
2. Expand the pool of potential projects funded under the current program by relaxing the cost neutrality requirement.		X		
3. Identify additional sources of funding to cover costs associated with financial incentives.	X			

Care for People with Significant Challenges Behaviors	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
Expand Capacity for Crisis Response and Stabilization				
<i>Develop and disseminate dementia assessment tools for use by crisis response and stabilization teams.</i>				
1. In coordination with experts and stakeholders, develop and disseminate an assessment tool for crisis response teams to use when working with a person who has dementia.	X	X		
<i>Promote dementia-capability in the existing mobile crisis response system.</i>				
1. Review current mobile crisis programs to identify common features of successful models		X		
2. Develop and pilot test a model for a dementia-capable mobile crisis response service focused on treating people in place.			X	
3. Identify one or more areas to pilot the model for effective dementia-capable mobile crisis response.			X	
4. Implement pilot, providing training and technical assistance and measuring outcomes.				X
<i>Explore amending DHS 34 to expand mobile crisis services and ensure they are dementia-capable.</i>				
1. Based on pilot results, determine if amendments to DHS 34 are warranted, including 24-hour mobile crisis response statewide.				X
Clarify Procedures for Emergency Protective Placement				
<i>Identify areas where clarification of emergency protective placement requirements and procedures are needed.</i>				
1. Review statutes and regulations on protective placement, including admission requirements, and identify likely areas where clarification for facilities may be helpful.	X			
2. Determine whether communication, such as a numbered memo, to facilities is warranted to provide clarification.		X		
Address the Shortage of Facilities Designated to Accept Emergency Protective Placements				
<i>Identify obstacles to designation of emergency protective placement facilities.</i>				
1. Work with DHS Research/Data Team to develop and administer a survey of facilities.	X			
<i>Identify and pursue options to address facility concerns and provide incentives to facilities designated as an Emergency Protective Placement Site.</i>				
1. Analyze data to identify barriers and develop incentives or solutions.	X			
2. Implement incentives or solutions.			X	X
<i>Explore the need for specialized facilities.</i>				
1. Consult with stakeholders, successful facilities and perform literary review to develop best practices.		X		

Care for People with Significant Challenges Behaviors	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
2. Disseminate models and provide training for replication.			X	
3. Examine results from the inventory of providers to determine whether further development of regional facilities is warranted.			X	
Dementia Care Standards and Training	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
Catalog and Publicize Existing Dementia Care Training Programs				
<i>Identify existing dementia care programs.</i>				
1. Survey stakeholders to identify currently available dementia training opportunities.	X			
<i>List training opportunities from the Department's expanded dementia care website.</i>				
1. Develop a process to update and disseminate the information.		X		
Develop Dementia Care Standards for Caregivers, Providers and Other Professionals				
<i>Research existing standards and best practices.</i>				
1. Review current policies, guidelines and best practices to provide a foundation for the development of dementia care standards.	X			
<i>Develop voluntary training standards for caregivers and other professionals involved with people with dementia.</i>				
1. Enter into an interagency agreement with the UW-Oshkosh Center for Career Development and Employability Training (CCDET) to create dementia care standards and associated training programs.	X			
2. Identify the categories of caregivers and other professionals for which training standards are to be developed (based on research on national standards, input from Wisconsin stakeholders, and input and approval from DHS).	X			
3. Develop and promote the use of the voluntary standards for caregivers and other professionals.		X		
<i>Develop Dementia Care Standards and a Voluntary Assurance Program for Facilities and Home Care Agencies.</i>				
1. Based on research on national standards, input from Wisconsin stakeholders, and input and approval from DHS, determine the different types of standards to be developed for facilities and home care agencies.	X			
2. Create a process under which providers or facilities could provide assurance related to meeting the standards.	X			
3. Make information available to the general public. Develop IT infrastructure (website structure) so information can be readily		X		

Dementia Care Standards and Training	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
accessible.				
4. Implement dementia care standards and assurance process for facilities and home care agencies.			X	
Provide Additional Training Opportunities Relating to Dementia Care				
<i>Develop a training program for caregivers and other professionals.</i>				
1. Based on training standards identified above, create training curricula and resource materials for dementia care training program.		X		
2. Launch a foundational training module for core dementia care training.		X		
3. Design and implement the IT infrastructure needed to offer a widely accessible training and certificate program.		X		
4. Develop widely accessible training program for caregivers and other professionals.			X	X
<i>Develop a competency testing and certificate program.</i>				
1. Develop competency testing based on information presented in training modules for caregivers and other professionals. Those who pass will be awarded a certificate of completion.		X		
<i>Create a registry of trained caregivers and professionals.</i>				
1. Develop an online registry of people who have completed the training program and received a certificate.		X		
2. Make online registry available to prospective employers and others looking for facility or home care services.			X	
Create Incentives for Compliance with Staff Training and Other Standards (Note: the following activities link to related initiatives in other sections.)				
<i>Promote voluntary use of standards and obtaining certificates of training (see Facility Based Long Term Care).</i>				
1. Encourage the voluntary use of standards and training programs by sharing information about them with the provider community, providing an opportunity for facilities and other providers to “brand” themselves as dementia-capable, creating a registry of those who have successfully completed an approved dementia care training program and earned a certificate, and informing consumers to look for services or facilities that have trained staff and comply with dementia care standards.		X		
<i>Encourage each MCO to work with contracted providers to follow the dementia care standards.</i>				
1. Work with MCOs to ensure that members with dementia receive dementia-capable care consistent with the standards developed.			X	

Dementia Care Standards and Training	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
2. Encourage each MCO to include provisions requiring compliance with state-approved dementia care standards in its contracts with facilities and other care providers.			X	
<i>Explore financial incentives for providers that comply with staff training and other dementia care standards.</i>			X	
1. Identify possible financial incentives for high quality dementia care through the Medicaid fee-for-service rate setting methodology.	X			
2. Encourage each MCO to build dementia care expectations and incentives into its contracts with nursing homes, assisted living facilities and community-based providers Because of the need for statewide accessibility and sustainability, in its provider network.			X	

Research and Data Collection	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
Develop and Implement Data Collection Plan to Facilitate Quality Measurement Related to Dementia Care				
<i>Identify data elements and sources for developing baseline measures.</i>				
1. Review and evaluate currently used and potential supplemental data sources to determine what information can be brought to bear as the dementia strategies are further developed and implemented.	X			
<i>Develop and employ metrics for measuring dementia care progress.</i>				
1. In consultation with stakeholders, develop performance indicators and establish key benchmarks to use in measuring progress in achieving Wisconsin's dementia vision and goals.		X		
<i>Collect and analyze data to determine baseline and quality improvement.</i>				
1. Evaluate the capacity and quality of Wisconsin's dementia care system and measure the progress made in achieving a more dementia-capable system of care.			X	
Inventory Providers of Dementia Care				
<i>Develop provider classifications relating to the dementia care services provided and acuity of the population served.</i>				
1. Convene a workgroup to develop facility classifications based on acuity.	X			
<i>Conduct a statewide inventory of dementia care facilities and services based on the level of dementia care they provide.</i>				
1. Develop an instrument to collect relevant information from counties, facilities and others.		X		
<i>Analyze data to evaluate the availability of dementia-capable care that</i>				

Dementia Care Standards and Training	Implementation Timeline			
	Jan- June 2014	July- Dec 2014	Jan- June 2015	Biennium 2015- 2017
<i>is appropriate for different acuity levels across the state.</i>				
1. Collect and analyze data to evaluate accessibility of appropriate care settings for different acuity levels across the state.			X	X
<i>Provide information to the public in an easily accessible and understandable format.</i>				
1. Disseminate information about the developed classifications related to levels of acuity, and the results of the provider inventory, using multiple means of communication designed to reach the intended audience.			X	
Analyze Cost Implications of the Strategies in the Plan				
<i>Perform an analysis of the fiscal impact of the strategies in the Plan.</i>	X			
1. Assess both short and long term funding needs to ensure successful improvements are maintained over time.				

Appendix C

Stakeholder Survey Report

Overview: Feedback from Partners

The Department of Health Services recognizes that achieving the goals set forth in the Plan for a Dementia Capable Wisconsin will require cooperation and coordination with the many partners involved in providing dementia care services. Therefore, the Department sought input on a draft of the Plan from partners throughout the dementia care network. Stakeholder feedback was collected through a web-based survey linked to the draft plan. Several individuals and organizations also prepared written responses to the Plan and submitted them directly to Secretary Kitty Rhoades. Finally, a few individuals addressed their comments to the Secretary verbally. Responses collected through each of these methods have been analyzed and taken into account in creating a revised Plan.

The stakeholder feedback survey included questions to assess how closely Plan priorities dovetailed with those of stakeholders. To begin, the survey asked respondents to label each broad strategic category either “top,” “medium,” or “low” priority. Respondents were then asked to discuss which strategies in each group they felt were most important and which required further clarification, through a series of open-ended comments. Respondents were also asked to assess how well the Plan addressed the priorities laid out in the Stakeholder Summit held in October, 2013, and were given an opportunity to provide any general comments or concerns regarding the Plan as a whole.

In all, 112 individuals responded to the online survey. Survey questions that could be quantified were summarized in a table showing the number and percent of respondents supplying each answer. These frequencies are most useful for a broad, general assessment of how closely the Plan’s initiatives hew to stakeholder priorities. The table is included below. To summarize, they show that, for each broad strategy, between 83% and 97% of respondents consider the strategy to be a “top” or “medium” priority, with between 3% and 17% considering the strategy a “low” priority. For all but four of the 13 initiatives, a majority (more than 50%) consider the initiative to be a “top” priority. The initiative that garnered the largest number of “top priority” responses was “Develop dementia care standards and additional training” (80.4%), while that with the largest “low priority” response was to “Promote dementia-friendly facility design” (17%).

How would you prioritize each of the Plan's strategic categories?						
Category	Top Priority		Medium Priority		Low Priority	
	Number	%	Number	%	Number	%
Community Awareness and Services						
Increase understanding and awareness of dementia	65	58.0%	39	34.8%	7	6.3%
Expand early identification and intervention	74	66.1%	34	30.4%	3	2.7%
Provide support for family caregivers	77	68.8%	27	24.1%	4	3.6%
Facility Based Care						
Address barriers that prevent families from admitting to facilities	73	65.2%	32	28.6%	3	2.7%
Improve the quality of dementia care provided in facilities	79	70.5%	29	25.9%	1	0.9%
Promote dementia-friendly facility design	45	40.2%	42	37.5%	19	17.0%
Challenging Behaviors						
Expand capacity for crisis response and stabilization	81	72.3%	25	22.3%	3	2.7%
Procedures for emergency protective placement	74	66.1%	28	25.0%	6	5.4%
Address the shortage of facilities designed to accept individuals	83	74.1%	20	17.9%	6	5.4%
Dementia Care Standards and Training						
Catalog existing dementia care training programs	29	25.9%	63	56.3%	15	13.4%
Develop dementia care standards and additional training	90	80.4%	11	9.8%	6	5.4%
Research and Data						
Develop and implement a data collection plan	43	38.4%	55	49.1%	6	5.4%
Inventory facilities providing dementia care and cognitive screening	54	48.2%	39	34.8%	11	9.8%

Similarly, the survey question about the Plan’s fidelity to the Wingspread Stakeholder Summit in October, 2013 provides a general sense of respondents’ evaluation of the Plan’s success at addressing Summit priorities. The largest share of respondents felt the Plan “adequately” addressed these priorities, with half or nearly half choosing this term in regard to each Summit priority (between 38% and 54%). Fewer (between 8% and 23%) felt the Plan addressed Summit priorities “very well,” though about one quarter assessed the treatment of “increased community awareness” this way. Respondents were least satisfied with the Plan’s treatment of the Summit priority to “create fiscal and systematic incentives” for best practices, with almost 37% saying the Plan did this inadequately or not at all.

Stakeholder perception of how well Plan addresses Dementia Summit priorities								
Dementia Summit Priority	Very well		Adequately		Inadequately		Not at all	
	Number	%	Number	%	Number	%	Number	%
Increased community awareness	26	23.2%	61	54.5%	7	6.3%	0	0.0%
Expand use of Dementia Care Specialist	24	21.4%	56	50.0%	15	13.4%	0	0.0%
Revise regulations - Safe Harbors	12	10.7%	45	40.2%	36	32.1%	1	0.9%
Create fiscal and systematic incentives	9	8.0%	42	37.5%	38	33.9%	3	2.7%
Expand mobile crisis teams	15	13.4%	54	48.2%	25	22.3%	0	0.0%
Create facility capacity	14	12.5%	49	43.8%	24	21.4%	3	2.7%

How comments were used to revise the Plan

While the broad overview afforded by the quantifiable questions is useful in general terms, open-ended comments provide more direction in terms of exactly what stakeholders want to see improved in the Plan. On the whole, comments made by survey respondents were very thoughtful and carefully crafted, and contained highly appropriate and useful suggestions. Some survey comments were aimed at gaps or shortfalls across multiple sections of the Plan, for instance pointing out the lack of explicit discussion of cultural competency, and noting a need for more detail on how tribes might be involved and impacted. Other comments were aimed at gaps in specific strategies. Examples include a suggestion to add mention of the National Family Caregiver Support Plan (Section 5.1.3); and a suggestion about training for DHS Division of Quality Assurance facility survey staff on the challenges of providing dementia services (Section 5.2.2).

All comments related to the five strategy categories were read and subject areas categorized and tallied to note the breadth of concern about specific issues. A summary of tallied items shows that largest number of respondents commented on the development of care standards and training and the promotion of training opportunities; on the need for measures to evaluate Plan success; and on the support of family caregivers.

Number and percent of stakeholder comments on Plan, by topic	Number	Percent of 112 Responses
Section 5.1: Community Awareness and Services		
Supporting family caregivers	40	35.7%
Expanding Dementia Care Specialist program	38	33.9%
Increasing awareness and understanding	34	30.4%
Dementia friendly communities	22	19.6%
Early identification and diagnosis	17	15.2%
Dementia capability of Managed Care Organizations	11	9.8%
Section 5.2: Facility-Based Long Term Care		
Best practice guidelines and federal flexibility to pursue them	32	28.6%
Training for facility staff	28	25.0%
Increased financial resources for facilities	28	25.0%
Dementia-friendly facility design	15	13.4%
Address barriers preventing admission	15	13.4%
Improve quality of facility care	12	10.7%
Section 5.3: Care for People with Significant Challenging Behaviors		
Shortage of "Chapter 55 facilities" and need for incentives	33	29.5%
Clarification of the procedures in Emergency Protective Placements under Chapter 55	28	25.0%
Development of assessment tool	7	6.3%
Mobile crisis teams	4	3.6%
Section 5.4: Dementia Care Standards and Training		
Promote training opportunities	47	42.0%
Develop standards of care/best practices	45	40.2%
Research existing best practices	15	13.4%
Section 5.5: Research and Data Collection		
Develop measures for assessing outcomes of strategies	45	40.2%
Inventory existing facilities	20	17.9%
Classify providers by various criteria	18	16.1%

In addition to survey responses, the Project Workgroup read carefully the written and summarized verbal communications received by Secretary Rhoades. With a thorough reading of all of these respondents' comments in mind, each section of the Plan was carefully analyzed for places that feedback could be used to clarify or to improve the strategies, or to facilitate their implementation. A detailed outline of the Plan was annotated with items from the Survey comments and other sources, and analyzed by Project Workgroup members. In many instances, suggestions addressed obvious gaps and were accepted and incorporated into the revised Plan without discussion (an example is the lack of specific mention of cultural competence, as noted above).

Other suggestions required modifications of the strategies, or elaboration of the implementation plans to encompass additional approaches (for instance, a strategy to address the workplace issues faced by family caregivers). When comments highlighted complex issues still lacking consensus in the dementia care community, the Dementia System Redesign

executive team and project management discussed them and made decisions about how best to address them. In some cases, project leadership determined that the Plan would include ongoing discussion and further strategy development in regard to complex issues. In other cases, suggestions were deemed out of scope for the current two-year Plan period, while warranting ongoing examination for future Department efforts. Among the latter are the development of transportation systems and of end-of-life care strategies crafted specifically for individuals with dementia.

A comprehensive list of the open-ended comments received from survey respondents, along with the written communications sent to Secretary Rhoades, is available on the Department website (include link to DHS priorities webpage for this initiative). Each respondent to the survey was assigned a number. Those numbers are listed alongside the survey comments to preserve confidentiality, while also allowing for the tracking of an individual's responses across the five strategic categories.

At the end of the stakeholder survey, respondents could indicate whether they would like to have ongoing involvement with the Dementia System Redesign project. A significant number of respondents signaled their interest in each topic area. For example, more than half of the total of 112 (n=57) said they would like to be involved with strategies to address the "Care for Individuals With Significant Challenging Behaviors." As DHS moves toward implementation, some strategic initiatives will require partner involvement as resources and to provide ongoing feedback and evaluative commentary. Other initiatives will require partner involvement directly in the implementation teams. Interested partners will be contacted with more information about these opportunities for involvement.

While the official period for submitting comments via the Stakeholder Survey was very brief, DHS continues to welcome the thoughts and feedback of partners and stakeholders. Comments received after the Plan is finalized will be helpful and important for the teams working to implement the Plan's strategic initiatives. Please do continue to provide us with your thoughts as a crucial means of sharing in this project. As Secretary Rhoades summarizes the essence of the Dementia System Redesign, "we are all in this together," and the solutions we devise and accomplish will shape the world in which we live and grow older, for years to come.