

Briefing Paper on Dementia Care Standards



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Executive Summary

Wisconsin is on the forefront as it moves forward with the important process of establishing standards for dementia care. These standards will create an effective framework for designing and implementing a model that provides a dementia-capable Wisconsin and ensures a future that delivers important mission outcomes. During the period of development of standards the Department of Health Services, health care providers and associations, dementia and Alzheimer's associations and experts, consumers and other stakeholders will play a critical role in the success of the State's transformation efforts. The adoption of the standards will support care coordination, consumer awareness, quality of life and person-centered care, safety and consumer engagement as well as reducing costs in an era of increasing numbers of people with dementia.

The information in this *Briefing Paper on Dementia Care Standards* is intended to be an information resource for the standards development effort. It is based on a review by the University of Wisconsin Oshkosh (UWO), Center for Career Development and Employability Training (CCDET) of international as well as national standards, strategies and plans for dementia care. The review included analysis of literature, website and research material. This briefing document is intended to be used as a guide and summary of common elements related to the development and implementation of dementia care standards. It is not meant to be a prescriptive standards document, but rather a tool to be used to identify potential key standard areas that may be considered to create a dementia-capable Wisconsin.

There are ten major common areas found in the review that relate to standards that are included in this document. Each area has a focus in providing person-centered care to individuals with dementia and creating a dementia-capable Wisconsin. They include:

- Early Diagnosis
- Promoting Autonomy and Choice
- Rights of People with Dementia and Their Families
- Staffing and Training Requirements
- Health and Personal Care
- Challenging Behaviors
- Resident Activity Programs and Lifestyle
- Physical Design of Facilities and Safety
- Community Awareness
- Integrated Services

This document will be used as a resource for participants of the May 2014 standards workgroup meetings to provide a starting point for their discussions.

Purpose of Standards

Establishing dementia care standards is essential and important to people with dementia, their families and the community, healthcare and social service providers and staff, and other entities, stakeholders and potentially all citizens of Wisconsin. Standards will provide a common language to assure consistency across the State and enhance understanding of rights, responsibilities and available support to enable a dementia-capable Wisconsin. Standards will also bring confidence and capability to businesses, consumers and government resulting in increased knowledge and awareness, improved efficiency and quality with costs controls, and more streamlined and effective care delivery, safety and quality outcomes.

Specific Quality Standards and How They are Measured

It will be important to develop quality standards that are outcome based and measurable. Because the standards will be based on people with dementia and their care, each standard outcomes measurement may be different. Measuring each standard allows using the availability of outcome information to make informed policy decisions or strategies, monitor issues and create viable solutions and provide consumers information to assist in making choices.

Measurement of each specific standard may be done in a variety of ways depending on what appropriately applies in determining an outcome. Methods that may be used to gather information to determine outcomes could include feedback and surveys, reports from current data systems, internal and external audit reports, individual case reports, review of internal policies and procedures, and capturing process indicators (e.g. delivery of care, quality of life, person-centered care approaches and satisfaction). Examples of how dementia standards are measured can be found under both the Scotland and United Kingdom standards of care for dementia.

Standards Review Results

Below are ten major subsections on areas of focus that are important considerations in the development of dementia care standards. The areas selected were found to be consistently indicated as significant in the development of a comprehensive and high quality system of support for dementia care. Materials reviewed included international and national standards, strategies, papers and plans.

Two countries in particular, Scotland and the United Kingdom, have developed comprehensive quality standards regarding dementia care that were reviewed extensively. Both countries' standards included statements and actions needed to support the standards as well as quality measures and outcomes.

Early Diagnosis

Early diagnosis of dementia is a key area of focus in international dementia plans for most countries as well as a part of the United States' National Plan to address Alzheimer's. It is also a part of the standards for Scotland which indicate people with dementia have a right to receive a timely and accurate diagnosis.

In addition, many State plans developed throughout this country include early detection and diagnosis strategies. Information on these strategies can be found in the Alzheimer's Association State Plans comparison document and in the state plans located at the following Alzheimer Association website:
http://act.alz.org/site/PageNavigator/state_plans.html

The early diagnosis of dementia can have many positive affects for the person as well as cost benefits. The ability of the person with dementia to participate actively in important decisions tends to deteriorate as the condition advances. The earlier dementia can be detected the more advanced planning can be done. Based on an early diagnosis, the person with dementia may also be able to make choices about how care is to be planned and delivered based on her/his preferences. People with dementia may also wish to legally appoint someone to make decisions for them as capacity declines. In addition, if detected early the progression of dementia may be decreased. Additional information on the benefits of early diagnosis can be found at the Alzheimer's Alliance website at:
<http://www.alzwisc.org/Importance%20of%20an%20early%20diagnosis.htm>

Promote Autonomy and Choice

The World Alzheimer Report 2013 developed by Alzheimer's Disease International cites promoting autonomy and choice as one of the essential principles and actions to be considered by all nations in developing comprehensive systems of care and support for people with dementia. The report indicates that people with dementia and their at-home caregivers need choices and control over decisions regarding the care and support they receive throughout their lives. This includes choices having to do with care and treatment, care arrangements, place of residence and end of life decisions.

An example of a standard of care regarding this area is in the Scotland Standards of Care for Dementia which indicates that people with dementia will have their individual needs, preferences and aspirations met. The standard regarding this also includes action items a service provider would ideally take to ensure this happens as indicated below:

Service providers will ensure that the actions of their staff and their policies and procedures demonstrate the following:

- Care plans are person-centered and strive to maintain the relationships, natural supports and routines important to the person with dementia.
- Systems are in place to collect and share information from the person with dementia and/or their caregiver about their personal preferences, choices and expectations of the service.
- Knowledge of whether the person with dementia has legally appointed someone to represent them.
- The person with dementia retains as much choice in day-to-day activities as possible, e.g. what and when to eat, when to get up and go to bed, when to go outside.
- Staff use a variety of communication aids to help communication, including the use of life story books, talking mats, digital stories, interpreters as appropriate and referral to speech and language specialists.

An additional example is the United Kingdom Quality standard for supporting people to live well with dementia. <http://publications.nice.org.uk/quality-standard-for-supporting-people-to-live-well-with-dementia-gs30>.

Under that standard there are quality statements such as choice and control in decisions, review of needs and preferences, leisure activities of interest, and maintaining and developing relationships. Each statement has a quality measure with structure and outcome information.

Rights of People with Dementia and Their Families

Recognizing and protecting the rights of people with dementia and their families provides a foundation for quality of life and care. Person-centered dementia care ensures protection of individual and family rights. Person-centered dementia care is care centered on the whole person rather than the disease of the brain. It focuses on the abilities, emotions and cognitive capacities of the person with dementia. Equal credence is given to psychosocial and physical/medical care.

The Standards of Care for Dementia in Scotland outline the following rights for a person with dementia:

- The right to a diagnosis.
- The right to be regarded as a unique individual and to be treated with dignity and respect.
- The right to access a range of treatment, care and support.
- The right to be as independent as possible and be included in the community.
- The right to have caregivers who are well educated about dementia.
- The right to end of life care that respect individual wishes.

Staffing and Training Requirements

Throughout the United States, as well as internationally, it is considered critical that staff from the health, social care services and other fields that interact or care for people with dementia have appropriate training to ensure the knowledge, skills and abilities to understand and provide needed services. The training and education of staff facilitates the ability for these professionals to provide proper information, resources, care and support services which enables quality of life and promotes decision making choices and options for people with dementia and their families.

Internationally, countries that have standards in place, such as Scotland and the United Kingdom, include training for caregivers and staff in health and social care agencies as a quality dementia standard for providers of service. In addition, review of international and national strategies and plans reveals that a majority focus on providing appropriate training and education for healthcare staff and others.

In the United States approximately 28 states have Dementia/Alzheimer's plans and 26 of those plans include training recommendations to better equip health care professionals and others to deal with individuals with dementia. Information on these strategies can be found in the Alzheimer's Association State Plans comparison

document and in the state plans located at the following Alzheimer Association website: http://act.alz.org/site/PageNavigator/state_plans.html

In addition, below are examples of states that have training requirements or have proposed legislation for training requirements for Dementia/Alzheimer's special care units or programs:

- Massachusetts Long-term care facilities and Dementia Special Care Units (DSCUs) are now required to provide eight hours of initial dementia-specific training for staff, and four additional hours of training per year. This training is required for medical directors, nurses, social workers, dietary aides, therapists, activities staff, and other direct-care workers to ensure the best possible care and quality of life for residents with dementia.
- Connecticut state law requires Alzheimer's special care units or programs to annually provide dementia-specific training to all staff as follows:
 - for all licensed and registered direct care staff, at least eight hours of training completed within six months of beginning employment followed by at least three hours annually thereafter; and
 - for unlicensed and unregistered staff providing care and services to residents, at least one hour of training completed within six months of beginning employment (CGS § [19a-562a](#)).

The Connecticut law applies to “Alzheimer's special care units or programs” in any nursing home, residential care home, assisted living facility, adult day center, hospice, or adult foster home.

- Illinois also has legislation that requires long-term care unit directors and staff to receive dementia care and ability-centered training. All staff who work on the unit (e.g., nurses, certified nursing assistants, housekeepers, social services and activities staff, and food service staff) are required to receive at least four hours of dementia-specific orientation within the first seven days of working on the unit. There are additional detailed requirements and continuing education hours for both the unit director and staff that work on the unit.
- Minnesota has proposed legislation (HR 2437, introduced in 88 Legislature 2013-14) that would require training on Alzheimer's disease for all long-term care facilities. The new law would require facilities to ensure that all direct care staff have at least eight hours of training prior to resident interaction and also be required to take eight hours of additional training on an annual basis. In addition, all non-direct care staff are required to have at least four hours of training prior to having resident interaction and two additional hours of training on an annual basis.

- Florida House Bill 573 and its companion Senate Bill 248 are intended to make changes to State Statute 429.178(2)(a) and would require assisted living facilities to provide staff with at least four hours of dementia-specific training. The training is to be developed or approved by Florida’s Department of Children and Families.

According to the Connecticut Office of Legislative Research Report August 3, 2012, five states (Alabama, Illinois, Iowa, North Dakota, and Missouri) require dementia training for home health aides. The table below summarizes these states' requirements.

State Dementia Training Requirements For Home Health Aides

State	Training Requirement
Alabama	The Department of Mental Health and Mental Retardation's Bureau of Geriatric Psychiatry, upon receipt of sufficient funding, must train health care providers and other caregivers who care for people with Alzheimer's disease and related disorders at home. The training must (1) encourage the provision of long-term care for the person in his or her home and (2) reduce health care costs to the state, the person's family, and health care facilities (AL ST § 22-50-72).
Illinois	The Department of Public Health, in cooperation with the Department on Aging, must develop specialized training and experience criteria for people who provide health or home care to people with Alzheimer's disease or related disorders (IL ST § 20 2305/5.5).
Iowa	The Department on Aging must train, within available funding, those who regularly provide services to people with Alzheimer's disease and related disorders, including home health care workers. Initial training for direct care staff must include eight hours of classroom instruction and eight hours of supervised interactive experiences. Direct care staff must also complete eight hours of continuing and in-service education annually (IA ST § 231.62).
North Dakota	The Department of Human Services must contract with a private provider for a dementia care services program in each area of the state served by a regional human service center. These services must include training care providers (presumably, this includes home health aides) to manage and care for people with dementia (ND ST § 50-06-33).
Missouri	Dementia training must be provided to people employed by in-home and home health agencies, adult day centers, assisted living and residential care facilities, or nursing homes providing services to people with dementia. Training must include an overview of the disease, communicating with people with dementia, behavioral management, promoting independence with activities of daily living, and understanding and dealing with family issues (MO ST § 191.115).

Health and Personal Care

Treatment and care should take into consideration the needs and preferences of a person with dementia. The individual should have the opportunity to make informed decisions about care and treatment in partnership with her/his healthcare professionals. If the person with dementia does not have the capacity to make her/his own decisions, healthcare staff should discuss these with the legally authorized representative.

United Kingdom Quality Care Standard for supporting people to live well with dementia includes quality statement #6: Physical and mental health well-being. The statement indicates that people with dementia are enabled, with the involvement of their caregivers, to access services that help maintain their physical and mental health and wellbeing. The Scotland Standards of Care for Dementia state that people with dementia receive treatment that is likely to be of benefit, including a range of non-drug based treatments.

The majority of state plans include care and case management recommendations that are intended to improve the individual health care for people with dementia/Alzheimer's. Information on these strategies can be found in the Alzheimer's Association State Plans comparison document and in the state plans located at the following Alzheimer Association website: http://act.alz.org/site/PageNavigator/state_plans.html

Challenging Behaviors

Changes in the behaviors of a person with dementia are common as dementia progresses and may create challenging situations. This can reduce the person's quality of life; increase caregiver stress; and increase the need for intervention strategies or changes in living arrangements that may be costly. There are numerous reasons why a person's behaviors may be changing. Dementia is a result of changes that take place in the brain and affects the person's memory, abilities, mood, communication and behavior. In addition, there may be changes occurring in the capacity to perform activities of daily living such as dressing or bathing. Also changes in environment including living arrangement, health, medication and lifestyle may trigger challenging behaviors. Recognizing unmet needs and providing person-centered approaches to care help provide the skills to respond appropriately in sometimes challenging situations.

Quality Care Standards in the United Kingdom include the Dementia quality standard, Quality statement #7: Non-cognitive symptoms and behaviour that challenges. The standard indicates that people with dementia who develop non-cognitive challenges that cause them significant stress or who develop challenging behaviors need to be offered an assessment at an early opportunity to establish the reasons and factors for those behaviors or stress. It also states that interventions to improve the behavior or distress should be recorded in the care plan. The Scotland Standards of Care for Dementia also

include information and examples of behavior challenges related to specific standards regarding dignity and respect, and access to a range of treatment, care and support.

Activity Programs and Lifestyle

It is important that people with dementia can take part in activities during their day that are meaningful to them. This is essential wherever they are living. All people have different interests and preferences about how they wish to spend their time and people with dementia are no exception. However, those with dementia will increasingly need the support of others to participate. Understanding this and knowing how to enable people with dementia to take part in activities can help maintain and improve their quality of life.

Based on Massachusetts law 105 CMR 150, facilities in that state that have Dementia Special Care Units (DSCUs) are required to have at least one therapeutic activities director on staff to ensure that residents are engaged in meaningful and appropriate activities. The activities are to be individualized, suited to residents' needs and interests, and designed to improve or maintain their abilities and functioning.

The United Kingdom Quality Care Standard for supporting people to live well with dementia includes quality statement #4: Leisure activities of interest and choice. The statement indicates "people with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice."

The Scotland Standards of Care for Dementia state that people with dementia will have the opportunity to be included in community life and meaningful activities as they wish. Services providers are required to give people with dementia the support they need wherever they are living, to be able to be involved in ordinary activities such as: exercise, music, dance, social events and religious activity, and to have opportunities to become involved in new activities and experiences.

Physical Design of Facilities and Safety

The physical design of facilities and homes where people with dementia live plays an important role in the area of safety and quality of life and care of people with dementia. United Kingdom Quality Care Standard for supporting people to live well with dementia includes quality statement #7: Design and adaption of housing. It provides that people with dementia live in housing that meets their specific needs.

There are also many articles and publications related to creating a home-like environment for persons with dementia. The Innovative Designs in Environments for an Aging Society website at <http://www.ideasconsultinginc.com/articles.asp> includes some

articles of interest in this area. Also in the Wisconsin Department of Health Services *Person-Directed Dementia Care Assessment Tool*, environment is an area of specific focus. In that document environment includes:

- Sound Level
- Ambiance
- Space Configuration
- Lighting, Colors/Patterns
- Visual Cues
- Personalization of Space

The tool is a guide for creating quality of life and for refocusing behavior for people with dementia in long term care settings.

In addition, Massachusetts law 105 CMR 150 includes requirements for designing dementia-friendly environments in Dementia Special Care Units (DSCUs). The law provides that units are to be resident-centered and focused on supporting residents' visual, lighting, spatial, recreational, and safety needs.

Community Awareness

According to the Wisconsin Dementia Care Redesign Plan, one of the categories that the Department of Health Services intends to strengthen is community awareness and services. The plan indicates this is based on the fact that three out of four people with dementia live at home in their local communities, and of these 22 percent are living alone. Support from the community can be an essential resource in the dementia care system and may help delay or prevent the need for institutional care and promote quality of life for people with dementia and their at home caregivers.

In the United States in states that have Dementia/Alzheimer's plans, the majority of those plans include public awareness recommendations to increase awareness of dementia/Alzheimer's disease among the public. Information on these strategies can be found in the Alzheimer's Association State Plans comparison document and in the state plans located at the following Alzheimer Association website:

http://act.alz.org/site/PageNavigator/state_plans.html

Integrated Services

The United Kingdom and Scotland both have quality standards for dementia that include language on the coordination of services across all relevant agencies that provide care. An integrated approach to provision of services is considered fundamental to the delivery of high quality care to people with dementia. The coordination and integration of services is also promoted in the World Alzheimer Report 2013 as a way to develop a

comprehensive and high quality system of support. Additional information can be found at: <http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>

One of the bases for the promotion of integrated services is that people with dementia, their families and at home caregivers are often unaware or confused about services, treatments and supports that are available due to the variety of health and social care providers. Professionals and agencies may not interact or communicate with each other. This can cause them to be unaware of all the issues or services involved in the person's care. This can result in problems with accurate treatment, assessment and/or support. The potential fragmentation of dementia care services can also adversely affect people with dementia, increase family and family caregiver burden and cause increased costs.

Conclusions

Research indicates having standards for dementia care affords tangible benefits on many levels, from improved quality of life and care to significant cost savings. The ten topic areas addressed within this briefing document have consistently been found to be essential to the development of dementia care standards within the United States and internationally. Outcomes associated with the implementation of effective standards include:

- Supporting care coordination;
- Raising consumer awareness;
- Ensuring quality of life and person-centered care;
- Increasing safety and consumer engagement;
- Reducing caregiver stress; and
- Reducing costs in an era of increasing numbers of people with dementia.

There are many valuable resources/references available to support Wisconsin's efforts to move forward with the development and implementation of dementia quality standards. While not all-inclusive, the references listed in this briefing document represent a broad spectrum of resource material.

This briefing document is intended to be used as a guide and summary of common elements related to the development and implementation of dementia care standards. It is not meant to be a prescriptive standards document but rather a tool to be used to identify potential key standard areas that may be considered to create a dementia-capable Wisconsin.

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TITLE 77: PUBLIC HEALTH CHAPTER I: DEPARTMENT OF PUBLIC HEALTH
SUBCHAPTER c: LONG-TERM CARE FACILITIES SKILLED NURSING AND
INTERMEDIATE CARE FACILITIES CODE SECTION 300.7050 STAFFING includes
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See SUBPART U: ALZHEIMER'S SPECIAL CARE UNIT OR CENTER PROVIDING
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HEALTH FACILITIES AND REGULATION
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<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1470659/>

In the introduction of the book, titled "Standards of Care in Dementia in Europe—A Consensus," EDCON gives 6 general recommendations for the care of patients with dementia: standardization in care; standards that are evidence-based and applicable to the different sites of care (home as opposed to a long-term care facility, for example); a partnership between patients, their care-givers, and their health care and social workers; carefully planned services; preservation of the dignity of the patient; and support of the caregiver.
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