Fall 2018 Dementia Care Certification Work Group
Summary of Agreement/Disagreement Areas

Background

- Dementia is a general term for memory loss and other cognitive abilities serious enough to interfere with daily life.
- Alzheimer's disease is a degenerative brain disease and the most common form of dementia.
- Alzheimer's is a progressive disease, where dementia symptoms gradually worsen over a number of years. In its early stages, memory loss is mild, but with late-stage Alzheimer's, individuals lose the ability to carry on a conversation and respond to their environment.
- 94,000 Minnesotans living with Alzheimer's.
- 1 in 10 people age 65+ has Alzheimer's dementia. 1 in 3 people age 85+ has Alzheimer's dementia.
- 60% of people with dementia live in the community, 25% of whom live alone.
- Individuals diagnosed with Alzheimer's live for an average of 4-8 years, some as long as 20 years.
- Long duration and high care needs associated with Alzheimer's means many individuals living with the disease are high users of long-term care.
- Some people living with dementia require increasing assistance with activities of daily living (ADLs) such as bathing and dressing, and independent activities of daily living (IADLs) such as cooking and managing finances.
- Not all people living with dementia require special services, particularly those in the early stages of the disease.
- For some people living with dementia, there may come a time when their individual needs cannot be met in a particular setting; the progression of the disease exceeds the scope of services offered in some settings.
- 60,000 people living in Assisted Living facilities in Minnesota
- 28,000 residents in Nursing Homes in Minnesota
- Approximately 42% of residents in Assisted Living facilities have dementia
- Approximately 61% of residents in Nursing Homes have dementia
- A little over a third (625 of 1,718) of Housing with Services facilities in Minnesota are registered as special care units, i.e. considered dementia or memory care.
- People living with dementia are served outside of special care units as well.

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Definitions

How terms are used below, not recommended statutory definitions:

- Assisted Living – means a long-term care setting licensed under the contemplated Assisted Living License.
- Dementia – is an umbrella term including Alzheimer's dementia and other dementias.
- Dementia care setting – means any assisted living facility that secures, segregates, or provides a special program or special unit for residents with Alzheimer's disease or other dementias or that advertises, markets, or otherwise promotes the establishment as providing specialized care for Alzheimer's disease or other dementias or "memory care."

Problems

- Minnesota guidelines and standards for dementia care are weak and vague.
- Individuals and families experience confusion understanding complex regulatory environment, mix of statutes related to Housing with Services/Assisted Living and Home Care.
- In addition to complex laws in different sections of Minnesota statute, some laws are vague, making it difficult for providers to understand the statutory requirements or how they are expected to meet expectations, and they receive inconsistent or conflicting information from Home Care & Assisted Living Program surveyors and Office of Health Facility Complaints investigators
- LTC ombudsman representatives are seeing an increase in concerns and problems at Housing with Services/Assisted Living settings related to dementia care.
- MDH Home Care & Assisted Living Program regulators do not have the authority to address some of the serious problems observed at Housing with Services/Assisted Living settings in survey process, and resources to conduct surveys are not adequate to meet current statutory requirements.

Vision

1. Minnesota laws and regulations will ensure that all long term care settings serving people living with dementia:
    a. provide person-centered dementia care based on thorough knowledge of the care recipient and their needs;
    b. advance optimal functioning and high quality of life;
    c. incorporate problem solving approaches into dementia care practices; and
    d. provide safe environment while recognizing each resident's autonomy and person-centered care needs, and a stable environment with minimal involuntary moves, which can be particularly difficult for a person living with dementia.
2. People with dementia may live in settings that are integrated with individuals that do not have the same needs or in dementia-specific care settings.
3. MDH will have appropriate authority and adequate financial and staff resources for consistent and timely surveys and enforcement.
4. Residents across Minnesota will maintain access to high quality dementia care.
5. Dementia care standards will align with the Home and Community Based Settings Rule standards to support continued access to Medical Assistance waiver funded services.

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Challenges

We discussed many related issues that we recognized we could not overcome in our limited time focused on dementia care standards, but want to identify them as existing challenges. In some cases, there is work happening elsewhere to address these issues.

- Workforce - difficult to recruit, retain, train adequate staff.
- Increased costs associated with additional, new regulation.
- Fluctuations in the long term care market, i.e. the natural ebb and flow of business in long-term care.
- Elderly Waiver payments may not be enough to cover costs associated with people living with dementia.

General Recommendations

These recommendations were developed in consideration of the simultaneous work happening in the Assisted Living License Work Group regarding a new license framework. These recommendations should be considered to ensure high quality care for people living with dementia under the new license framework, whether that is in a general population (some people with dementia, some people without) or within a dementia care specific setting.

Text marked green indicates where we have agreement/yellow where we might be able to get there with more work/red where there were unresolved disagreements.]

1. People living with Alzheimer's disease or other dementias are not required to reside in a dementia care setting.
2. There should be additional license or certification requirements – i.e. minimum standards and disclosure – for dementia care settings.
3. Since people with dementia will live in all types of long-term care settings, all assisted living settings should meet minimum dementia training requirements.

Implementation

Our group recognized and contemplated the difficulties related to how new minimum standards are implemented, in conjunction with the new assisted living license, without hindering access to living options for people living with dementia. We did not have sufficient time to make recommendations about implementation, but here are some issues we discussed/questions we asked but did not answer.

- How and when does the state require minimum standards to be met for new construction settings?
- Do we have a base understanding of what housing and service models exist currently and do we know what would be required of providers to ensure compliance with any new standards?
- Should these new dementia requirements be effective immediately or phased in over a period of time?
    - If phase-in is allowed, how do consumers know when and how that is happening in a particular setting?
    - What is the right time-frame by which all settings must comply with minimum standards?

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Minimum standards/requirements for Dementia Care Settings

- Should not be in conflict with nursing home dementia standards. Standards for dementia care in Assisted Living need not mirror current nursing home regulations but should take the general approach into account so the standards for each setting do not conflict.
- Staff have the skills, training, and education to assess and provide care for a resident population with dementia. (See "Training" for detailed info.)
- Activity programming based on physical and cognitive abilities and interests of residents. … takes into consideration the resident's cognitive ability, memory, attention span, language, reasoning ability, and physical function, and includes a person-centered plan for engaging residents in programming.
- Behavior support plan that emphasizes nonpharmacological practices to address behavioral and psychological symptoms of dementia (BPSD).
- Medical management to maximize health and well-being for people with dementia, including when nonpharmacological measures fail, medications, including antipsychotics, which may be necessary and appropriate to relieve the person with dementia's distress.
- Physical environments to promote safety and minimize confusion and overstimulation, including secure settings responsive to person-centered assessed needs.
- 24-hour awake staff on-site.
- Disclosure to regulators, the public, residents and families on issues related to being a dementia care setting. (See "Disclosure" for detailed info.)

Disclosure for Dementia Care Settings

Building on/editing existing disclosure requirements in 325F.72 for special care status:

- To whom disclosure is required: Subd 1
  - MDH will review disclosures as part of the survey process.
  - Will be publicly available.
- Content: Subd. 2
  - Add to (2) [criteria for who can live there] Pre-admission, admission and discharge info/the process and criteria for placement within, transfer/discharge from a dementia care setting if needed.
  - Add to (4) [staffing credentials] Staffing patterns based on the needs of the patient mix and needs at the time, staff coverage, staff to resident ratios for all shifts.
  - Add to (5) [physical environment] Emergency procedures/safety plans for unique challenges faced by residents with dementia.
  - MAARC phone # and other resource list
  - Identify any minimum standards (as outlined in 2019 new statutes) not currently met and a timeline for meeting them. [Consider as a part of minimum dementia standards implementation and sunset after mandatory compliance date.]
- Remedy: Subd 4
  - Give authority to MDH in addition to/instead of the Attorney General to enforce by penalty/suspending/terminating license.

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Training for all Assisted Living Settings

Building on existing dementia training statutes for home care and housing with services.

Dementia training should incorporate principles of person-centered dementia care including knowledge of the person, their history, interests, abilities and needs; advancement of optimal functioning and a high quality of life; and use of problem solving approaches to care. New and existing care providers should be trained adequately and appropriately to best address the needs of the population of care recipients they serve. And training should be culturally competent, both for the provider and the care recipient.

- Require dementia training for all care providers employed by an assisted living facility and who are involved in the delivery of care or have regular contact with persons with Alzheimer's disease or related dementias;
- Use a culturally competent training curriculum that incorporates principles of person-centered care and how to best address the needs of care recipients;
- Require an evaluation of staff competency through demonstration of skills and knowledge gained through training; monitored by MDH;
- Establish a system to support and enforce continuing education on dementia care;
- Allow portability of completed dementia care training across employment settings;
- Ensure trainers meet minimum requirements to qualify as instructors of dementia care curriculum; and,
- MDH formally monitors/evaluates dementia training programs as part of assisted living licensing and ensure compliance with state dementia training requirements.
- Shorten the timeframe from date of hire until dementia training must be completed.
- Increase total hours of staff training, including annual training;
- Require direct supervision for direct care until hours are completed;

Curriculum: Build on existing training requirements in 144D.065 for housing with services, to ensure initial training covers the following topics:

- Dementia, including the progression of the disease, memory loss, psychiatric and behavioral symptoms;
- Strategies for providing person-centered care;
- Communication issues;
- Techniques for understanding and approaching behavioral symptoms, including alternatives to physical and chemical restraints;
- Strategies for addressing social needs and providing meaningful activities; and
- Communication of information on how to address specific aspects of care and safety unique to people with dementia (e.g. pain, food and fluid, wandering).

Additional training considerations for dementia care settings:

- Shorten the timeframe from date of hire until dementia training must be completed.
- Require on-the-floor supervision by trained, competent staff of any untrained staff until dementia training is completed.

Other guidelines

Our group discussed these items in depth, and while we did not feel they rise to the level of being a minimum standard that must be met, we felt they should be considered as guidelines, considerations or best practices for dementia care settings. In some cases, we struggled to define what higher bar should be met for dementia care over what we understand is being recommended for all residents in the Assisted Living License discussion.

- Provide assistance, education and coordination of services for transitions to new setting that can take care of a resident's person-centered care needs.
- Staff collaboratively assess, plan, and provide coordinated care that is consistent with current advances in dementia care practices, including any restrictions based on assessed needs of an individual. Initial assessment should include gathering of personal history and interests of the individual that will be shared with staff to support awareness and person-centered care and programming.
- Consideration of enriched environments that facilitate engagement with animals, the outdoors, children, etc., based on the interests of the individual.

Issues to relay to other work groups for consideration

- **Assisted Living License:** generally these ideas/recommendations are to inform the work of the Assisted Living License Work Group. We did not address all of these areas because we understand that they will be covered in the AL license discussion:
  - Assessment and care planning basics.
  - Transitions in care.
  - Physical plant standards.
- **Consumer Rights:** We understand they are working on:
  - Consumer rights regarding discharges/terminations
- **Assisted Living Report Card** - Should consider inclusion of:
  - Use of antipsychotic medications
  - non-medical interventions for behavioral expressions
  - Therapeutic activities
  - Safe & supportive environments
  - Or all minimum standards for dementia care settings

Participants in these discussions to create recommendations included:

Alzheimer's Association Minnesota-North Dakota Chapter
Leading Age Minnesota
Care Providers of Minnesota
Individual long-term care providers
Paid direct caregivers
Minnesota Elder Justice Center
Office of the Minnesota Long Term Care Ombudsman
Minnesota Department of Health
Minnesota Department of Human Services
Individual dementia consultants
Individual elder Law attorneys

Resources:

- Discussions between members of this work group.
- Alzheimer's Association Dementia Care Practice Recommendations:
- Dementia Care: The Quality Chasm
- The Joint Commission on Dementia Care Accreditation and Certification

Person-centered focus is the core of quality dementia care

We referenced the following image from the Alzheimer's Association's care practice recommendations, which outline recommendations for quality care practices based on a comprehensive review of current evidence, best practice and expert opinion.