



Legislative Report

Alzheimer's Disease Working Group

January 2019

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Cover letter

To the Governor and Legislature of Minnesota:

As the Alzheimer's Disease Working Group, our singular focus for the past year has been to identify actions necessary to improve Minnesota's capacity to address the needs of almost 100,000 Minnesotans living with Alzheimer's disease and other dementias, and to prepare the state for an even larger wave of Minnesotans who will become afflicted by these diseases in the next decade.

While researchers around the world are exploring a myriad of approaches to halt or prevent Alzheimer's disease and other dementias, these approaches are probably at least 10 years away. And while the disease predominantly attacks our aging population, young-onset dementia affects tens of thousands of Minnesotans in their younger years.

Without the immediate prospect of a cure, our report concentrates on other ways in which the state can make a positive impact on the Minnesotans living with this disease and those committed to their care. Each recommendation we have included plays an integral part in changing the future for so many Minnesotans. Your actions will have a powerful impact on the lives of thousands of people living with Alzheimer's disease or other dementias, while ultimately reducing the cost of these diseases to our state. It is a goal worthy of your effort.

It has been my privilege and honor to serve as chair of the 2018-2019 Alzheimer's Disease Working Group. I was diagnosed with Mild Cognitive Impairment (MCI) in June 2015. Since that time, I have been actively involved in dementia advocacy and a number of research projects conducted by organizations across Minnesota. With some accommodations, I am living well with the disease. Other Minnesotans with Alzheimer's disease and other dementias don't have as positive a story to share. Minnesota can and must do more to change their life stories.

We are extremely proud of the work we have done in preparing this report. For ten months, over 75 Minnesotans were involved on the working group and its five supporting committees to update the 2011 Report *Preparing Minnesota for Alzheimer's: The budgetary, social, and personal impacts*. Whether our perspective was as a care partner/caregiver, researcher, clinician, professional care provider, or person living with the disease, we came together and shared our stories, expert knowledge, and hopes. The working group tackled the challenge of distilling all that was discussed into the most important and specific actions the state can take to respond to the full impact of Alzheimer's disease and dementia. The next important steps are up to you.

Respectfully,

Darrell G. Foss
Chair, 2018 Alzheimer's Disease Working Group

Acknowledgments

The Alzheimer’s Disease Working Group greatly appreciates the time, effort, and expertise of all community members who participated in the recommendations and report development—they were forthcoming with information and expertise and generous with their time. Their dedication, resourcefulness, and thoughtfulness made this report possible. A full list of participants in the process can be found in Appendix A and Appendix B. The working group also thanks the Minnesota Board on Aging and its staff for handling our group logistics, and Management Analysis and Development for meeting facilitation and report writing. Special thanks to those listed in Appendix C.

Glossary of terms and acronyms

Terms

Alzheimer’s disease: Encompasses a continuum beginning with initial brain changes that start years before symptoms appear and continue with years of symptoms that affect cognitive and physical function. The disease continuum ends with severe impairment, when brain changes are so extensive that individuals can no longer control muscle movement and struggle to eat, drink, and communicate.¹

Dementia: A group of symptoms that includes difficulties with memory, language, problem solving, and other cognitive skills. Alzheimer’s disease is a degenerative brain disease and the most common cause of dementia.

Dementia-capable: An ability (a combination of staff knowledge, skills, and competency as well as available programs and services) to fulfill the needs of persons with dementia and their caregivers.² For instance, dementia-capable health care systems have been defined as “those that provide individualized, coordinated, and integrated medical and psychosocial care for patients and their care partners, delivered by cohesive teams of clinicians, staff, and health care administrators.”³

Dementia-friendly: A dementia-friendly community is “a village, town, city or county that is informed, safe and respectful of individuals with the disease, their families and caregivers and provides supportive options that foster quality of life.”⁴

Mild Cognitive Impairment (MCI): “A condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but the individual is still able to carry out everyday activities.”⁵

Acronyms

DHS – Minnesota Department of Human Services

MBA – Minnesota Board on Aging

MDH – Minnesota Department of Health

Note: Throughout the report, state agencies’ names are written in full in each recommendation; agencies’ acronyms are used in the explanations.

¹ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” (2018): 1-6, accessed December 6, 2018, <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>.

² Shih-Yin Lin and Frances Marcus Lewis. “Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future.” *The Gerontologist* 55, no. 2 (2015): 237-244.

³ Soo Borson and Joshua Chodosh. “Developing Dementia-Capable Health Care Systems: A 12-Step Program.” *Clinics in geriatric medicine* 30, no. 3 (2014): 395-420.

⁴ Dementia Friendly America®, “About DFA,” accessed December 11, 2018, <https://www.dfamerica.org/what-is-dfa/>.

⁵ Ibid: 10.

Executive summary

To address the growing public health issue of Alzheimer’s disease and other dementias, the 2017 Minnesota Legislature reconvened the Alzheimer’s Disease Working Group. The Legislature charged the group with reviewing and revising the 2011 report *Preparing Minnesota for Alzheimer’s: The Budgetary, Social and personal impacts*, including creating findings and recommendations to the Legislature in the following seven topic areas:

1. Health care data on trends and disparities in cognitive decline
2. Public awareness
3. Risk reduction
4. Diagnosis and treatment
5. Professional education and training
6. Residential services
7. Cultural competence and responsiveness⁶

The working group met five times in 2018 to formulate its findings and recommendations. Throughout its discussions, the working group emphasized the importance of the voices of people directly impacted by the disease, attention to elder abuse in long-term care settings, a shared commitment to cultural responsiveness and equity, and a belief in the power of stories to influence change.

Key findings

An estimated 5.7 million Americans are living with Alzheimer’s disease, including more than 94,000 Minnesotans as of 2018, and these numbers are expected to grow dramatically (see Figure 1).⁷ The number of Minnesotans affected by Alzheimer’s disease is estimated to be 120,000 in 2025.⁸ In 2016, an estimated 2,219 Minnesotans died as a result of Alzheimer’s disease, making it the sixth leading cause of death in Minnesota.⁹

Minnesota is still not fully prepared to address the impact of Alzheimer’s disease and other dementias on Minnesotans. Many previous efforts “to prepare” the state, while well intentioned and successful in their own right, have been fragmented. These include data collection efforts, public awareness messaging and campaigns, professional training expectations, regulatory enforcement, and licensing systems. Similar to the 2011 working group, the 2018 working group believes “Minnesota needs a much stronger and comprehensive statement on Alzheimer’s disease.”

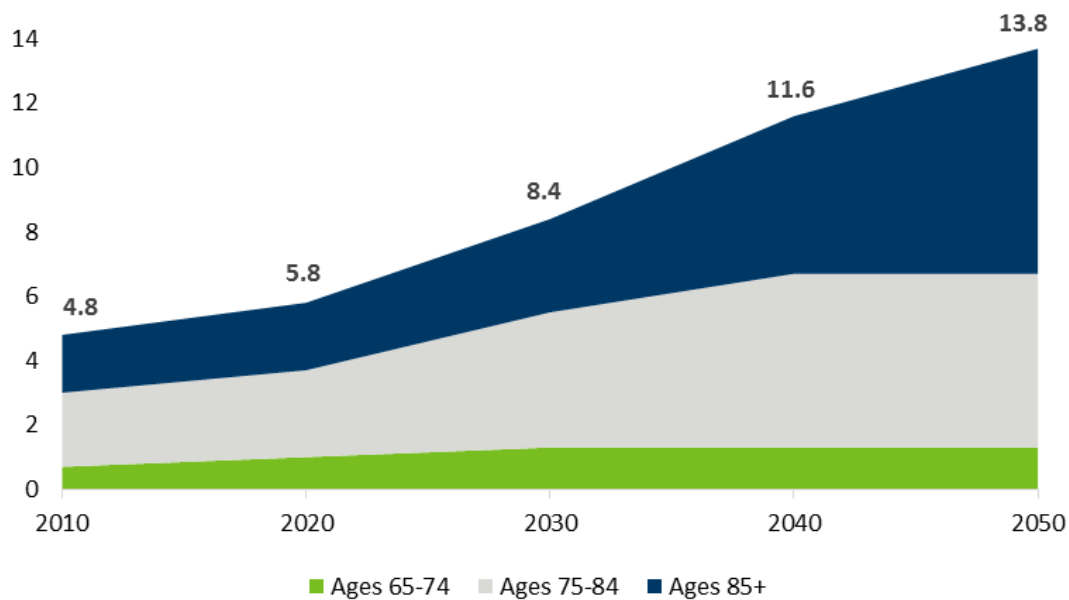
⁶ Minnesota Session Laws, 2017, 1st Spec. Sess., chapter 6, article 3, section 48.

⁷ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” (2018): 17, accessed December 6, 2018, <https://www.alz.org/media/HomeOffice/Facts%20and%20Figures/facts-and-figures.pdf>.

⁸ Alzheimer’s Association–Minnesota and North Dakota Chapter, accessed December 6, 2018, <https://www.alz.org/mnnd>.

⁹ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, “Stats of the State of Minnesota,” accessed December 6, 2018, <https://www.cdc.gov/nchs/pressroom/states/minnesota/minnesota.htm>.

Figure 1: Projected number of people age 65 and older in the U.S. population with Alzheimer’s Dementia, 2010 to 2015 (in millions).



Note: Figure based on data from Hebert et al.¹⁰

Minnesota’s long-term care health workforce is experiencing a severe shortage, limiting the state’s ability to effectively and compassionately care for Minnesotans affected by Alzheimer’s disease and other dementias. By 2025, one in five Minnesotans are predicted to be over the age of 65, and 70 percent of those are expected to need long-term care services at some point.¹¹ At the same time, Minnesota’s health care workforce is aging, and wages in certain health professions are low, especially direct care.^{12, 13} Some of the greatest long-term care health workforce needs are in rural areas and among traditionally underrepresented communities.¹⁴

¹⁰ Liesi E. Hebert, Jennifer Weuve, Paul A. Scherr, and Denis A. Evans. “Alzheimer Disease in the United States (2010–2050) Estimated Using the 2010 Census.” *Neurology* 80, no. 19 (2013): 1778-1783.

¹¹ Minnesota State Demographic Center, “Demographic Considerations for Long-Range and Strategic Planning,” (March 2016): 3-4, accessed December 6, 2018, https://mn.gov/admin/assets/demographic-considerations-planning-for-mn-leaders-msdc-march2016_tcm36-219453.pdf.

¹² Ibid: 7-8.

¹³ Minnesota Department of Human Services, “Status of Long-Term Services and Supports.” Legislative report. August 2017, accessed December 16, 2018 https://mn.gov/dhs/assets/2017-08-long-term-services-supports_tcm1053-309107.pdf. See also: Department of Human Services, “Direct Care/Support Workforce Summit: Summary Report and Next Steps,” (2016), accessed January 9, 2019, <https://edocs.dhs.state.mn.us/lfsrserver/Public/DHS-7271A-ENG>. The report’s appendices, including presentations by the Minnesota State Demographer and State Economist, can be found here: <https://edocs.dhs.state.mn.us/lfsrserver/Public/DHS-7271C-ENG>.

¹⁴ Teri Fritsma, “Supply and Demand of Health Care Workers in Minnesota,” (2017), accessed December 11, 2018, <http://www.health.state.mn.us/divs/orhpc/workforce/documents/pdf/2017mhasupplydemand.pdf>.

No medical treatment can prevent or cure Alzheimer’s disease. While there is currently no way to prevent, cure, or slow the progression of Alzheimer’s disease, important research in treatment, prevention, and cures continues across the world. In pursuing dementia research, researchers face obstacles ranging from lack of funding to lack of participants in clinical studies. This is despite large federal and state investments in Alzheimer’s disease and dementia research over the last few years. Investments in medical research have, however, led to better disease detection.

Alzheimer’s disease is more prevalent among certain population groups. Two-thirds of Americans with Alzheimer’s disease are female. Older African-Americans are about twice as likely to have Alzheimer’s or other dementias as older whites. Hispanics are also more likely to have Alzheimer’s. Although the exact increased likelihood is unclear, it could be as high as one and a half times as whites.¹⁵

The disease has significant social and economic impacts on families, communities, organizations, and the state. In 2017, researchers estimated that the total nationwide costs for paid care of people living with Alzheimer’s exceeded \$250 billion.¹⁶ This is in addition to the unpaid work of an estimated 25 percent of all adults who provide care or assistance to a person with a long-term illness or disability, including dementia. Nationwide, their unpaid caregiver activity is worth approximately \$232 billion.¹⁷

Public awareness and knowledge of Alzheimer’s disease remains relatively low. According to a 2018 AARP poll, most Americans have a high level of exposure to information about people living with dementia and other diseases affecting cognitive ability. Despite this, they lack knowledge about key characteristics of the disease. For instance, three-quarters of respondents incorrectly believe that memory loss is a normal and natural part of aging, and almost half of American adults incorrectly believe treatments are available to slow or stop the progression of Alzheimer’s disease.¹⁸

Not everyone experiences Alzheimer’s disease and other dementias in the same way. People affected by Alzheimer’s disease and other dementias are not a homogenous group, and the same is true for their families, caregivers, and communities. Cultural norms and values regarding Alzheimer’s vary significantly, as do norms regarding caregiver roles.

¹⁵ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” 20-21.

¹⁶ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, “Alzheimer’s Disease: Promoting Health and Independence for an Aging Population at a Glance,” accessed December 6, 2018, <https://www.cdc.gov/chronicdisease/resources/publications/aag/alzheimers.htm>.

¹⁷ Ibid.

¹⁸ Laura Mehegan, “Alzheimer’s Disease and Dementia Awareness Poll 2018,” AARP.org, accessed December 6, 2018, <https://www.aarp.org/research/topics/health/info-2018/alzheimers-dementia-awareness.html#quest1>.

Updates since 2011 report

While no entity formally tracked the recommendations from the 2011 legislative report, the following progress has occurred:

- **ACT on Alzheimer's®:** One powerful initiative that emerged from the 2011 Alzheimer's Disease Working Group was ACT on Alzheimer's®, a public-private, Minnesota-based collaboration. While the original initiative has concluded its work, other organizations are continuing ACT on Alzheimer's® work.¹⁹
- **Medical and research advancements:** In Minnesota, 2015 legislation provided annual Alzheimer's research grants of \$500,000 to the Mayo Clinic and University of Minnesota. In 2011, the Centers for Medicare and Medicaid Services implemented Annual Wellness Visits for all Medicare Beneficiaries under the Patient Protection and Affordable Care Act. A mandatory part of the Annual Wellness Visit is an assessment for detection of cognitive impairment.
- **MBA dementia grants:** In 2015, the Minnesota Legislature created a competitive grants program administered by the Minnesota Board on Aging (MBA). The program focuses on dementia and its impacts on persons with dementia, family and friend caregivers of persons with dementia, and communities. The Legislature appropriated \$1.5 million per biennium for this grant program.

While the state has seen progress in many ways, some of the 2011 report's suggested areas for improvement have seen less progress and still need work:

- **Public awareness:** Minnesota does not have a collaboratively led, statewide, coordinated public awareness campaign for memory impairment or Alzheimer's disease and other dementias. Gaps remain regarding the consistency and clarity of information currently provided to Minnesota communities.
- **Residential services:** While multiple associations and organizations have created "best practices" or standards of care, the use of these recommendations or practices is not required or monitored in Minnesota. As a result, the methods, models, and quality of care for individuals with dementia vary widely across care settings.
- **Cultural responsiveness:** Some efforts have been made to address dementia in culturally diverse populations, including the creation of Minnesota Board on Aging's Cultural Consultants. Important gaps still remain, including data availability, access to culturally sensitive information, and culturally responsive health care providers.

Guiding values

The working group established the following foundational values for approaching the development of their recommendations. Members stressed that these values should be foundational to those who enact these recommendations.

¹⁹ For more information, see ACT on Alzheimer's®, "ACT's Evolution and Structure: 2017 to 2018," accessed December 6, 2018, <http://actonalz.org/pdf/evolution.pdf>.

Authenticity

- Accept people where they are. Whether someone is an individual with one of these diseases, a family member, or a provider, we are all responsible for playing an active role in health equity and cultural responsiveness.
- Providers and those in positions of power must be open to hearing and learning about different needs. They must also positively address expressed concerns, showing that they have sought and fully heard the voice of the client, patient, and/or caregiver.

Assets-based approach to equity and diversity

- There are many variations of families, and caregiving can look different. A patient is an individual as well as a reflection of one's culture and family norms. Consider the needs of families and caregivers who may have different cultural norms and values related to Alzheimer's disease and other dementias, as well as families where the care structure is not a husband-and-wife team.
- Communities have many different norms regarding how they view elders and dementia. An equitable solution may mean that different groups need different things, rather than a one-size-fits-all approach.

Openness to discussion and out-of-the-box ideas

- Acknowledge through constructive dialogue the role that race and racism has played, and continues to play, in creating the dementia care policies and procedures that provide services and support for some individuals while denying them for others. These dementia care programs and processes have been a product of the dominant culture's assumptions without input from those who are not of that culture, but who deserve "a seat at the table" of decision making.
- Actively create opportunity for voices that have been hidden to participate in ideation and decision making that may create meaningful outcomes for communities of color and Indigenous peoples.

Overarching recommendations

When reflecting on the breadth of recommendations that emerged from their eight-month process, the working group felt compelled to include two overarching recommendations central to the state's ability to prepare itself for Alzheimer's disease and other dementias. If the state does not address these two broad recommendations, the state will not be able to respond successfully to many of the more specific recommendations. These overarching recommendations are discussed in more detail on page 34.

A. Comprehensive accountability for state actions on Alzheimer's disease and other dementias

Key representatives from the Minnesota Legislature, the Minnesota Department of Human Services, the Minnesota Department of Health, and the Minnesota Board on Aging must determine how and where to centralize planning and coordination of all state efforts related to mitigating the impact of Alzheimer's disease and other dementias in Minnesota.

B. Prioritize and invest in health care workforce development

The Minnesota Legislature should prioritize and invest in the development of the state's health care workforce, with an emphasis on:

1. attracting and retaining new and diverse people to health care professions with the largest shortages;
2. ensuring continuous education and training in dementia care; and
3. enhancing the portability/transferability of training, skills, and certifications.

Recommendations by story

The working group organized their specific recommendations around five “stories” that envision a new reality for Minnesota's response to Alzheimer's disease and other dementias. Each story relates to a broader area of concern and what they believe the state should do to positively influence those concerns. The stories are shared in more detail on page 38 of this report.

A data-rich state

1. Install a recommendation tracking system

Designate an entity within state government to monitor the state's progress on implementing the working group's recommendations. This will end a reliance on external work group reviews, and will make monitoring accomplishments a part of the state's larger strategic plan for health and aging services.

2. Improve overall quality, collection, and accessibility of the state's dementia-related data

Require more individual and coordinated efforts by the Minnesota Department of Health and the Minnesota Department of Human Services to improve the quality and availability of dementia-related data. Everyone involved in efforts that will positively impact the realities of this disease should have access to the data.

3. Increase access to health care system and community data

The state should authorize the Minnesota Department of Health to obtain community data from Minnesota-based health care systems. This will allow them to develop and implement programs and policies that improve care and foster a nurturing, supportive environment for people with dementia and their caregivers.

Entrusting our care in dementia-capable professionals

4. Increase funding for clinical training at sites that serve populations with a high prevalence of dementia

The Minnesota Legislature should provide additional funding for clinical training at sites that serve populations with a high prevalence of dementia, such as nursing homes, assisted living facilities, adult day service providers, and home health agencies. They should either amend funding formulas for Medical Education and Research Costs (MERC) grants to include such sites or should appropriate additional funds.

5. Make clinical training at nursing facilities eligible for MERC funding

The Minnesota Legislature should revise Minnesota Statutes 62J.692 to remove the exclusion of clinical training at nursing facilities from receiving MERC grants.²⁰

6. Train health care professionals at Minnesota State Veterans Homes

The Minnesota Department of Veterans Affairs' State Veterans Homes (SVH) should partner with higher education institutions and other governmental organizations to help create a workforce prepared to provide long-term care services, including dementia care. The SVH are committed to providing comprehensive dementia training to improve quality of care, person-centered care, and resident satisfaction. This could be accomplished through comprehensive training of medical, dental, nursing, behavioral health, and other health care professional trainees.

7. Prioritize and incentivize reporting on Alzheimer's disease outcomes

The state, including the Minnesota Legislature and state agencies such as the Minnesota Department of Human Services and the Minnesota Department of Health, should prioritize and incentivize outcomes reporting on Alzheimer's disease by medical providers. Outcomes that should be reported include, but are not limited to, the number of screenings/assessments, the number of people diagnosed with Alzheimer's disease and other dementias, and the number and types of referrals to other resources.

8. Require training on cognitive impairment through health care licensing boards

The state should encourage Minnesota's health care professional licensing boards to require training on detecting, managing, and caring for patients with cognitive impairment as part of their continuing education requirements. This would include the Minnesota Board of Behavioral Health and Therapy, the Minnesota Board of Medical Practice, the Minnesota Board of Marriage and Family Therapy, the Minnesota Board of Nursing, the Minnesota Board of Examiners for Nursing Home Administrators, the Minnesota Board of Psychology, and the Minnesota Board of Social Work.

9. Increase care providers' use of ACT on Alzheimer's® practice guidelines

State agencies and boards responsible for public health, such as the Minnesota Department of Health and the Minnesota Board of Medical Practice, should promote sharing and routine use of ACT on Alzheimer's® practice guidelines for the detection and management of cognitive impairment and dementia in primary and specialty care within all Minnesota health systems.²¹

²⁰ MDH annually distributes MERC grants to providers of clinical medical education. These grants are used to fund a portion of the costs for clinical training of health professionals in Minnesota. MERC funds come from several sources, including cigarette tax revenue, federal Medicaid matching funds, and a carve-out of medical education funds from the Prepaid Medical Assistance Program.

²¹ Another resource on standards of dementia care is the Alzheimer's Association's "2018 Dementia Care Practice Recommendations," accessed January 9, 2019, <https://alz.org/getmedia/1a0020aa-0bfb-47ac-a545->

A family member and caregiver's story

Alzheimer's disease has changed our family's life forever, like in any case when a terminal illness takes the life of somebody significant in your life. In our case, this was our still very young mother.

Alzheimer's disease creates a destructive path. Dementia impacts not only the person who has the diagnosis, but everyone in their lives. It causes so much pain and suffering for those closest to them. It can destroy families, cause financial hardships, and loss of work. It will challenge and ask the best from medical professionals and social workers to caregivers and therapists. Alzheimer's disease puts a crippling mental stronghold on everyone it touches.

Legislators must know that this is not just a geriatric disease, in which people get a little forgetful. **Legislators must know its destructive nature and the mental, physical, and financial challenges that come along with it.** It cannot be stopped or even slowed down at this point, which gives families little hope. Greater public awareness, early education, and better community support and resources are essential.

All homes are safe homes

10. Review, strengthen, and expand the rights of vulnerable adults in long-term care settings

The Minnesota Department of Human Services, the Minnesota Department of Health, and the Ombudsman Office for Long-Term Care should review, strengthen, and expand the rights of vulnerable adults living in long-term care settings and their families. Improvements should focus on care that is more person-centered and culturally responsive, and on enhancing criminal and civil enforcement when violations of the Home Care and Health Care Bill of Rights occur.

11. Clearly define Minnesota's dementia care standards across residential settings

The state should use existing resources to develop and adopt consistent baseline standards of person-centered care practices for individuals living with dementia in all types of long-term care facilities. Currently nursing homes must meet federal minimum standards for person-centered care that address issues related to care planning, staff training, therapeutic activities, and physical environments. However, other long-term settings such as housing with services and assisted living facilities are only required to disclose their philosophy and practice guidelines, and the government has no authority to enforce those self-disclosed standards. This inconsistency is confusing and sometimes harmful to Minnesotans.

[1dd8a3ee1444/alzheimers-dementia-care-practice-recommendations](https://www.dhs.gov/1dd8a3ee1444/alzheimers-dementia-care-practice-recommendations). This document was published as supplement to the February 2018 issue of The Gerontologist.

12. Establish a license for assisted living facilities

The state should give the Minnesota Department of Health the authority to establish a license for assisted living settings. It should be consistent with existing standards of care for persons with dementia and aligned with regulations in other settings.

13. Adopt a Minnesota Family and Medical Leave Act that includes “parent-in-law” in the definition of family members for which an employee can take unpaid leave

The Minnesota Legislature should adopt a Minnesota Family and Medical Leave Act that mirrors the federal Family and Medical Leave Act, but includes a more expansive definition of “family” to include parent-in-law, following precedents from other states.

People are supported every step of the way

14. Provide more information and counseling along the entire care continuum

The Minnesota Board on Aging should reevaluate the long-term care counseling process and the information provided through Senior LinkAge Line. Information should be provided in more consumer-friendly formats that supports patient and family decision making and general understanding of long-term care living options in Minnesota.

15. Promote early detection and diagnosis and incentivize treatment of Alzheimer’s disease and other dementias as a chronic disease

The Minnesota Department of Health should reform health systems in Minnesota by promoting early detection and diagnosis of Alzheimer’s disease and other dementias. The Minnesota Department of Health should also incentivize the treatment of Alzheimer’s disease and other dementias as a chronic disease by keeping an up-to-date authoritative link on its website.

16. Improve regional networks of medical and community support

The state should actively support creative regional efforts to establish community dementia resource centers. These centers should work in partnership with each region’s medical community to create a better web of support for each resident needing services. This should include coordination with Tribal Nations and American Indian communities.

Living well with dementia

17. Coordinate a structured awareness campaign

The Minnesota Legislature should support a collaboratively led, coordinated, and statewide awareness campaign on Alzheimer’s disease and other dementias. This campaign should help reduce stigma, offer a balanced perspective of risks and treatment possibilities, and share how people adapt to and “live well” with a diagnosis of Alzheimer’s disease or other dementia.

18. Develop guidance for the medical community regarding specific safety risks faced by persons living with Alzheimer’s disease and their families

The Minnesota Department of Public Safety, the Minnesota Department of Health, and other relevant state agencies should convene a group of dementia experts, dementia clinicians and other pertinent community stakeholders to develop standards around risks and safety and Alzheimer’s disease and other dementias, including but not limited to driving and firearms and to recommend an implementation strategy that could include dissemination through ACT on Alzheimer’s® practice guidelines, continuing medical education standards, or other regulatory or statutory changes.

Legislation

Minnesota Session Laws, 2017, 1st Spec. Sess., chapter 6, article 3, section 48.

Sec. 48. Alzheimer's Disease Working Group.

Subdivision 1. **Members.**

- (a) The Minnesota Board on Aging must appoint 16 members to an Alzheimer's disease working group, as follows:
- (1) a caregiver of a person who has been diagnosed with Alzheimer's disease;
 - (2) a person who has been diagnosed with Alzheimer's disease;
 - (3) two representatives from the nursing facility or senior housing profession;
 - (4) a representative of the home care or adult day services profession;
 - (5) two geriatricians, one of whom serves a diverse or underserved community;
 - (6) a psychologist who specializes in dementia care;
 - (7) an Alzheimer's researcher;
 - (8) a representative of the Alzheimer's Association;
 - (9) two members from community-based organizations serving one or more diverse or underserved communities;
 - (10) the commissioner of human services or a designee;
 - (11) the commissioner of health or a designee;
 - (12) the ombudsman for long-term care or a designee; and
 - (13) one member of the Minnesota Board on Aging, selected by the board.
- (b) The executive director of the Minnesota Board on Aging serves on the working group as a nonvoting member.
- (c) The appointing authorities under this subdivision must complete their appointments no later than December 15, 2017.
- (d) To the extent practicable, the membership of the working group must reflect the diversity in Minnesota, and must include representatives from rural and metropolitan areas and representatives of different ethnicities, races, genders, ages, cultural groups, and abilities.

Subdivision 2. **Duties; recommendations.**

The Alzheimer's disease working group must review and revise the 2011 report, Preparing Minnesota for Alzheimer's: the Budgetary, Social and Personal Impacts. The working group shall consider and make recommendations and findings on the following issues as related to Alzheimer's disease or other dementias:

- (1) analysis and assessment of public health and health care data to accurately determine trends and disparities in cognitive decline;
- (2) public awareness, knowledge, and attitudes, including knowledge gaps, stigma, availability of information, and supportive community environments;
- (3) risk reduction, including health education and health promotion on risk factors, safety, and potentially avoidable hospitalizations;

- (4) diagnosis and treatment, including early detection, access to diagnosis, quality of dementia care, and cost of treatment;
- (5) professional education and training, including geriatric education for licensed health care professionals and dementia-specific training for direct care workers, first responders, and other professionals in communities;
- (6) residential services, including cost to families as well as regulation and licensing gaps; and
- (7) cultural competence and responsiveness to reduce health disparities and improve access to high-quality dementia care.

Subdivision 3. **Meetings.**

The Board on Aging must convene the first meeting of the working group no later than January 15, 2018. Before the first meeting, the Board on Aging must designate one member to serve as chair. Meetings of the working group must be open to the public, and to the extent practicable, technological means, such as Web casts, shall be used to reach the greatest number of people throughout the state. The working group may not meet more than five times.

Subdivision 4. **Compensation.**

Members of the working group serve without compensation, but may be reimbursed for allowed actual and necessary expenses incurred in the performance of the member's duties for the working group in the same manner and amount as authorized by the commissioner's plan adopted under Minnesota Statutes, section 43A.18, subdivision 2.

Subdivision 5. **Administrative support.**

The Minnesota Board on Aging shall provide administrative support and arrange meeting space for the working group.

Subdivision 6. **Report.**

The Board on Aging must submit a report providing the findings and recommendations of the working group, including any draft legislation necessary to implement the recommendations, to the governor and chairs and ranking minority members of the legislative committees with jurisdiction over health care by January 15, 2019.

Subdivision 7. **Expiration.**

The working group expires June 30, 2019, or the day after the working group submits the report required in subdivision 6, whichever is earlier.

Introduction

Background

An increasing number of Americans are living with Alzheimer’s disease and other dementias, including more than 94,000 Minnesotans as of 2018. The number of Minnesotans living with Alzheimer’s disease is estimated to grow to 120,000 in 2025.²² This has significant social and economic impacts on families, communities, organizations, and the state. An estimated 25 percent of American adults aged 18 or older provide care or assistance to a person with a long-term illness or disability.²³ Their unpaid care is in addition to the total costs of paid care for people living with Alzheimer’s disease, which were estimated to exceed \$250 billion in 2017.²⁴

Not everyone experiences these diseases in the same way. People affected by Alzheimer’s disease and other dementias are not a homogenous group, and the same is true for their families, caregivers, and communities. People who have and are affected by this disease cross every social and geographic line. As a result, cultural norms and values regarding Alzheimer’s disease and other dementias vary, as do the norms for caregiver roles. While most people affected by Alzheimer’s disease and other dementias are over the age of 65, about four percent are younger than 65. Consequently, a one-size-fits-all approach will not work. Minnesota needs a more equitable approach that is culturally responsive and takes into account this diversity.

To address this growing public health issue, the 2009 Minnesota Legislature directed the Minnesota Board on Aging (MBA) to convene an Alzheimer’s Disease Working Group to study the status of Alzheimer’s disease in Minnesota. The working group produced the 2011 report *Preparing Minnesota for Alzheimer’s: The Budgetary, Social and Personal Impacts*. The report contained recommendations to better prepare the state for future increases in the disease. Six years after the publication of this report, the 2017 Minnesota Legislature reconvened a working group and charged it with reviewing and revising the 2011 report, including creating findings and recommendations to the Legislature in the following seven topic areas:

1. Health care data on trends and disparities in cognitive decline
2. Public awareness
3. Risk reduction
4. Diagnosis and treatment
5. Professional education and training
6. Residential services
7. Cultural competence and responsiveness²⁵

²² Alzheimer’s Association—Minnesota and North Dakota Chapter, accessed December 6, 2018, <https://www.alz.org/mnnd>.

²³ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, “Alzheimer’s Disease: Promoting Health and Independence for an Aging Population at a Glance,” accessed December 6, 2018, <https://www.cdc.gov/chronicdisease/resources/publications/aag/alzheimers.htm>.

²⁴ Ibid.

²⁵ Minnesota Session Laws 2017, 1st Spec. Sess., chapter 6, article 3, section 48.

Updates since 2011 report

While no entity formally tracked the recommendations from the 2011 legislative report, this section documents the progress, changes, and inaction that have since then. Many valuable initiatives have taken place around the state, such as a public-private partnership between the University of Minnesota and HealthPartners, ACT on Alzheimer's® efforts to create dementia-friendly communities, and the Alzheimer's Association's work on early-stage support. At the same time, for many families affected by this disease, progress and change are not happening fast enough.

ACT on Alzheimer's®

One powerful initiative that emerged from the 2011 Alzheimer's Disease Working Group was ACT on Alzheimer's®, a public-private, Minnesota-based collaboration. The collaboration focused on:

- increasing detection and improving care and support;
- fostering “dementia-friendly” communities;
- supporting caregivers;
- raising community awareness; and
- seeking ways to reduce costs and improve care.

ACT on Alzheimer's® has developed a full array of provider practice tools for many audiences, ranging from primary care physicians, community-based providers, and care coordinators to persons with dementia and their caregivers. Tools on the ACT website include a protocol practice tool for detecting cognitive impairment, an electronic medical record decision support tool for dementia care, a protocol practice tool for mid- to late-stage dementia, care coordination practice tools, and tips and action steps to share with a person diagnosed with Alzheimer's disease.²⁶ Various communities, organizations, and businesses in Minnesota have already begun to implement these tools.

ACT on Alzheimer's® also produced a toolkit for communities interested in becoming dementia-friendly and administered a grant program to fund Minnesota communities' toolkit implementation. Nearly 50 Minnesota communities applied and received funding, and these communities are in various phases of becoming dementia-capable.

The resulting community and provider tools, research, and community impacts can be found on the ACT on Alzheimer's® website at www.actonalz.org. Although ACT on Alzheimer's® has concluded its work, it has had a

²⁶ For more information, see ACT on Alzheimer's®, “Provider Practice Tools,” accessed December 18, 2018, <http://www.actonalz.org/provider-practice-tools>.

positive impact on Minnesota and created a “ripple effect” across the country.²⁷ Other organizations and structures are continuing ACT on Alzheimer’s® work.²⁸

Medical and research advancements

In 2018, the federal government approved a \$425 million increase for federal Alzheimer’s disease and dementia research funding, bringing annual federal funding to \$2.3 billion.²⁹ In Minnesota, 2015 legislation provided annual Alzheimer’s research grants of \$500,000 to the Minnesota Partnership for Biotechnology and Medical Genomics. Minnesota’s research grants are for collaborative, two-year projects that neither institution could pursue alone. For instance, the 2018 grant was awarded to a project that investigates the role of tau proteins in mice and human cells to better understand whether blocking tau may be a way to treat Alzheimer’s disease.

Despite increases in research funding, there are currently no medical therapies that either cure or slow down the progression of Alzheimer’s disease. A recent review of scientific studies of interventions aimed to prevent or delay the onset of age-related cognitive decline, mild cognitive impairment (MCI), or clinical Alzheimer’s dementia showed no consistent and strong evidence for the effectiveness of any intervention, including cognitive training, physical activity, and drug treatment.³⁰ However, medical advances since 2011 include an increased ability to detect changes in the brain—so-called biomarkers—that can occur before the first symptoms of Alzheimer’s and related dementias occur. Research has also improved the medical community’s ability to identify genetic risk factors related to Alzheimer’s disease. Other research provides support for beneficial interventions for those living with dementia—such as home and community-based services, technologies, and rehabilitative services—as well as interventions on the health and well-being of caregivers.³¹

Finally, in 2011, the Centers for Medicare and Medicaid Services (CMS) implemented Annual Wellness Visits for all Medicare beneficiaries under the Patient Protection and Affordable Care Act. A mandatory part of the Annual Wellness Visit is an assessment for detection of cognitive impairment. However, this is only available to those over the age of 65 who are covered by Medicare.

MBA dementia grants

In 2015, the Alzheimer’s Association–Minnesota and North Dakota Chapter advanced legislation that called for significant funding to increase the likelihood of early identification, diagnosis, care consultation, and provision of resources. The Minnesota Legislature created a competitive grants program administered by the MBA that

²⁷ Gaby Galvin, “A Quest to Become Dementia-Friendly,” U.S. News, (February 1, 2018), accessed December 19, 2018, <https://www.usnews.com/news/healthiest-communities/articles/2018-02-01/minnesota-leads-states-in-fostering-dementia-friendly-communities>.

²⁸ For more information, see ACT on Alzheimer’s®, “ACT’s Evolution and Structure: 2017 to 2018,” accessed December 6, 2018, <http://actonalz.org/pdf/evolution.pdf>.

²⁹ Alzheimer’s Association, “Research and Progress: Milestones,” accessed December 11, 2018, https://www.alz.org/alzheimers-dementia/research_progress/milestones.

³⁰ National Institute on Aging, “Advances in Alzheimer’s Disease and Related Dementias Research,” accessed December 11, 2018, <https://www.nia.nih.gov/about/advances-alzheimers-disease-related-dementias-research>.

³¹ Ibid.

focuses on dementia and its impacts on persons with dementia, family and friend caregivers of persons with dementia, and communities. The Legislature appropriated \$1.5 million per biennium for this grant program.

The MBA awarded grants in 2015, 2017, and 2018. Grantees have worked on:

- Increasing cognitive testing, including enlisting family and friend caregivers to encourage a person with memory loss to seek testing.
- Promoting the benefits of early diagnosis of dementia. This includes screening for early memory loss among Somalis and African-Americans in public housing buildings that serve older adults, collaborating with businesses to identify and educate working family and friend caregivers, and training exercise professionals about safe exercise programs for people with dementia.
- Offering specific services responsive to the cultural norms and values of African-American, Native American/American Indian, Korean, Lao, Latinx, Russian, Somali, and lesbian, gay, bisexual, transgender, and queer (LGBTQ) cultures.³²

An MBA dementia grant recipient's story

We had a client a few years ago who we knew had been diagnosed with Alzheimer's disease. This person had two children, one who lived nearby and one who lived a distance away. One of the children understood what was going on with their mother but the other was in denial and refused to work with the other sibling and community resources in helping their mother access services that could help her live well and safely in her own home. They also did not assign one of the siblings to have power of attorney rights or act as a guardian. As a result the mother began wandering the streets at odd times and in all sorts of weather and bills went unpaid. **Ultimately both siblings got educated about how the disease was affecting their mother** and the mother ended up in a long-term care facility, perhaps earlier than would have been necessary. This is an example of **how important it is to address the living and financial situations of someone living with the disease, while the person can still be an active participant.**

[It gives us hope] that the state of Minnesota is committed to supporting the health research institutions at the Mayo Clinic, the University of Minnesota, and other organizations in leading the nation in finding a cure. And, until a cure is found, **it gives us hope that the state of Minnesota is supporting local communities** financially with grants to develop and maintain innovative and effective methods of supporting the caregivers and people living with Alzheimer's in their communities to live-well-safely-and-independently in their own home as long as possible.

³² For more information, see the MBA's annual reports to the Legislature on the dementia grants, available electronically here: <https://www.leg.state.mn.us/edocs/edocs?oclcnumber=973884041>.

Public awareness

Currently, Minnesota does not have a collaboratively led, coordinated, statewide public awareness campaign for memory impairment or Alzheimer's disease and other dementias. Since the working group last met in 2011, a broad set of stakeholders have initiated and continued efforts to educate and engage communities about Alzheimer's disease and other dementias, including through ACT on Alzheimer's® and the MBA dementia grants. Gaps remain regarding the consistency and clarity of information currently provided to Minnesota communities.

Multiple Minnesota-based websites and resources are available to promote public awareness:

- ACT on Alzheimer's® (www.actonalz.org)
- Alzheimer's Association–Minnesota and North Dakota chapter (www.alz.org/mnnd)
- Senior LinkAge Line (<http://www.seniorlinkageline.com/>)
- MinnesotaHelp.info (<https://www.minnesotahelp.info/>)
- Minnesota Board on Aging (www.mnaging.net)
- Minnesota Department of Health–Alzheimer's Disease and Related Dementias (www.health.state.mn.us/divs/hpcd/alzheimer/)

Residential services

While multiple associations and organizations have created “best practices” or standards of care, the use of these recommendations or practices is not required or monitored in Minnesota. As a result, the methods, models, and quality of care for individuals with dementia vary widely across care settings. Facilities differ in staff education and training, staffing levels, and understanding of dementia's symptoms and behaviors. Some facilities might be resistant to institutional change. As such, many programs and facilities serving those with Alzheimer's disease and other dementias struggle to provide compassionate, timely, and comprehensive care.

In 2017, Minnesota media outlets reported on a significant increase in maltreatment reports of elder Minnesotans in various residential settings to the Office of Health Facility Complaints. Governor Dayton's Consumer Workgroup recognized the need to closely examine the root causes of these reported complaints. Prior to the Consumer Workgroup, there had been significant advocacy to expand and enforce the rights of older adults by developing and enforcing a residential facility licensure framework.

Cultural responsiveness

Since 2011, some efforts have been made to address dementia-related concerns in culturally diverse populations. For example, the MBA supports Cultural Consultants, a service that provides cultural expertise and professional services to health care providers across Minnesota. These consultants have been specially trained in recognizing and understanding signs of memory loss, as well as offering resources to support caregiving family, friends, and neighbors. In addition, the MBA dementia grants have promoted awareness of Alzheimer's disease and other dementias in various communities and culturally-sensitive dementia care. The Alzheimer's Association has developed a relationship with the Comunidades Latinas Unidas en Servicio to better serve caregivers in the Latino community. Still, important gaps remain, including quantitative and qualitative data availability, access to culturally sensitive information, and culturally-responsive health care providers.

Overview of Alzheimer’s disease and other dementias in Minnesota

This section provides a brief overview of Alzheimer’s disease and other dementias, including national and state trends. It further discusses how Alzheimer’s disease affects certain population groups differently, and documents other noteworthy national research findings regarding Alzheimer’s disease, including public awareness, cultural responsiveness, residential care, and costs to the state and families.

Dementia, Alzheimer’s disease, and MCI

Dementia is a group of symptoms that includes difficulties with memory, language, problem solving, and other cognitive skills. Alzheimer’s disease is a degenerative brain disease and the most common cause of dementia. Alzheimer’s dementia impacts an estimated 5.7 million older adults in the United States, with more people affected by other dementias, such as frontotemporal dementia.³³

Alzheimer’s disease encompasses a continuum beginning with initial brain changes of Alzheimer’s (the emergence of amyloid plaques and neurofibrillary tangles). These brain changes start years before symptoms appear and continue with years of symptoms that affect cognitive and physical function. The late stages of Alzheimer’s disease are severe, when brain changes are so extensive that individuals can no longer control muscle movement and struggle to eat, drink, and communicate.³⁴ In other words, the disease consists of a preclinical, MCI stage and a dementia stage (also referred to as Alzheimer’s dementia). In the United States, one in 10 people age 65 and older live with Alzheimer’s disease. There is currently no known cure or prevention for the disease.

MCI is “a condition in which an individual has mild but measurable changes in thinking abilities that are noticeable to the person affected and to family members and friends, but the individual is still able to carry out everyday activities.”³⁵ Fifteen to 20 percent of people age 65 and older have MCI. MCI can be classified as amnesic and non-amnesic. People who suffer from the former are more likely to develop Alzheimer’s disease or other dementias.^{36, 37}

³³ Exact numbers of people affected by other types of dementia are unknown. A 2011 study estimated frontotemporal dementia impacts about 20,000-30,000 Americans. See: David S. Knopman and Rosebud O. Roberts. “Estimating the Number of Persons with Frontotemporal Lobar Degeneration in the US Population.” *Journal of Molecular Neuroscience* 45, no. 3 (2011): 330-335.

³⁴ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures.”

³⁵ Ibid.

³⁶ Robert Roberts and David S. Knopman, “Classification and Epidemiology of MCI.” *Clinics in Geriatric Medicine* 29, no. 4 (2013):753-72.

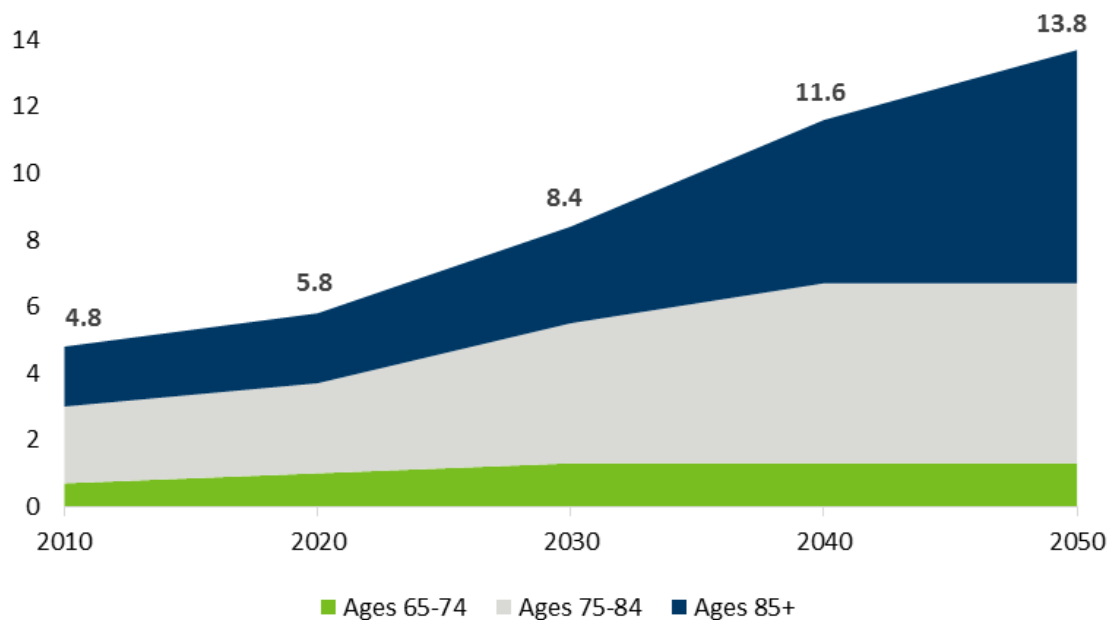
³⁷ Kejal Kantarci, Stephen D. Weigand, Scott A. Przybelski, Maria M. Shiung, et al. “Risk of Dementia in MCI: Combined Effect of Cerebrovascular Disease, Volumetric MRI, and 1H MRS.” *Neurology* 72, no. 17 (2009): 1519-25.

National trends

According to the Alzheimer’s Association’s 2018 *Facts and Figures* report, an estimated 5.7 million Americans currently live with Alzheimer’s disease.³⁸ The vast majority, over 95 percent, are people age 65 and older. Another 200,000 individuals under 65 have younger-onset Alzheimer’s disease. Since Alzheimer’s dementia is underreported and underdiagnosed, many more people may be living with the disease without being aware of it.

According to the national Centers for Disease Control and Prevention (CDC), the total number of Americans affected by the disease is expected to climb to almost 14 million by 2050 (see Figure 2).³⁹

Figure 2: Projected number of people age 65 and older in the U.S. population with Alzheimer’s Dementia, 2010 to 2015 (in millions).



Note: Figure based on data from Hebert et al.⁴⁰

³⁸ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” 17.

³⁹ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, “Alzheimer Disease: Promoting Health and Independence for an Aging Population at a Glance.”

⁴⁰ Liesi E. Hebert, Weuve, Jennifer L., Scherr, Paul A., and Evans, Denis A. “Alzheimer’s Disease in the United States (2010-2050) Estimated Using the 2010 Census.” *Neurology* 80, no. 19 (2013): 1778-83.

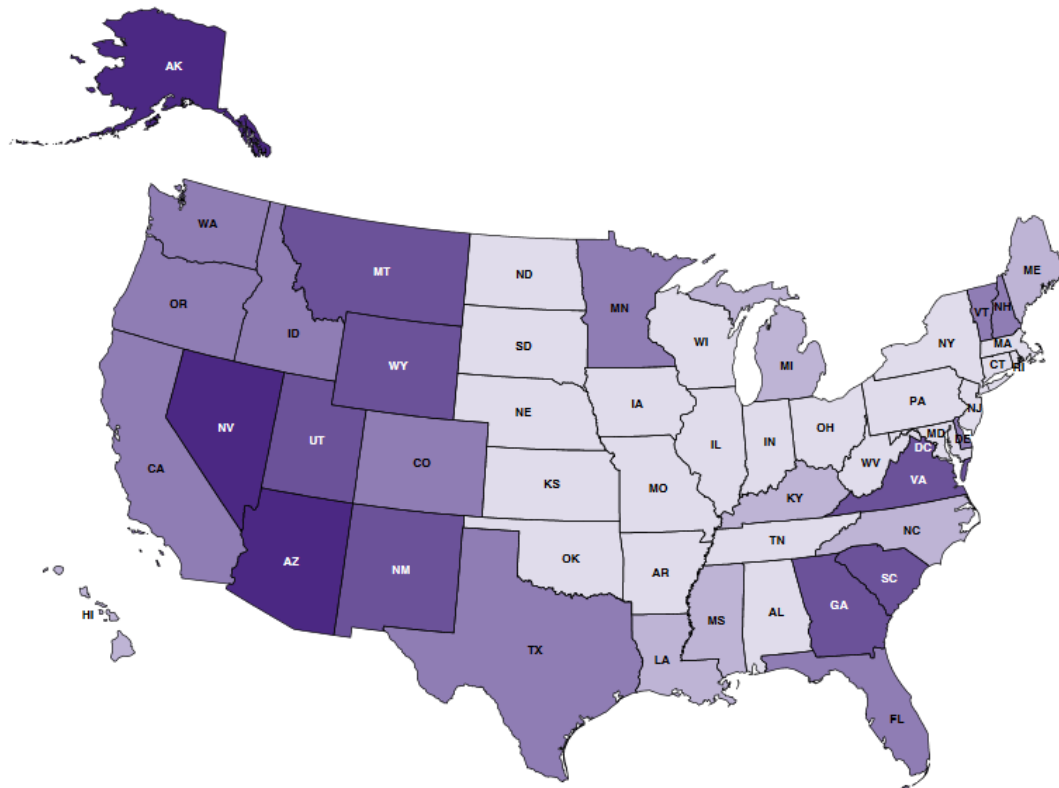
Trends in Minnesota

Over 94,000 Minnesotans are living with Alzheimer’s disease as of 2018.⁴¹ The Alzheimer’s Association predicts Minnesota will have 120,000 people living with Alzheimer’s disease in 2025, a 28 percent increase over 2018 (see Figure 3).

Figure 3: Projected increases between 2018 and 2025 in Alzheimer’s dementia prevalence by state.

Projected Increases Between 2018 and 2025 in Alzheimer’s Dementia Prevalence by State

13.6% - 20.2% 20.3% - 26.8% 26.9% - 33.5% 33.6% - 40.1% 40.2% - 46.7%



Change from 2018 to 2025 for Washington, D.C.: 1.1%

Created from data provided to the Alzheimer’s Association by Weuve et al.^{42,209}

In 2014, Alzheimer’s disease was the sixth leading cause of death in Minnesota, accounting for 1,628 deaths. That number rose to an estimated 2,219 in 2016.⁴² Minnesota’s death rate from Alzheimer’s disease has been

⁴¹ Alzheimer’s Association—Minnesota and North Dakota Chapter.

⁴² U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, “Stats of the State of Minnesota,” accessed December 6, 2018, <https://www.cdc.gov/nchs/pressroom/states/minnesota/minnesota.htm>.

growing: Minnesota had 24.2 deaths per 100,000 people in 2014, compared to 21.8 in 2016. In comparison, the nationwide death rate in 2016 was 30.3.

At the same time, the number of older adults in Minnesota is also increasing. The Minnesota State Demographic Center predicts “that Minnesota’s 65+ population will surpass the 5-17 (typical K-12 school-age) population by 2020, and that older adults will be more numerous than the entire child population under age 18 by 2035.”⁴³ This raises important questions regarding caregiving and shortages in the health care workforce as 70 percent of Minnesotans 65 and older are expected to use long-term care services at some point.⁴⁴

Trends by gender, ethnicity, and race

Alzheimer’s disease is more prevalent, on a per capita basis, among certain population groups. First, women are impacted by Alzheimer’s disease at a higher rate than men: two-thirds of Americans with Alzheimer’s disease are female. Additionally, “most studies indicate that older African-Americans are about twice as likely to have Alzheimer’s disease or other dementias as older whites.”⁴⁵ Hispanics are also more likely to have Alzheimer’s disease. Although the exact increased likelihood is unclear, it could be as high as one and a half times as whites.⁴⁶ It is also uncertain to what extent factors such as education, poverty levels, and discrimination account for these racial and ethnic differences. Regardless, these disparities are compounded by the fact that Alzheimer’s disease is more often undiagnosed among African-Americans and Hispanics than among whites.⁴⁷

Additional findings by topic area

Risk factors

There is currently no medical treatment that can prevent or cure Alzheimer’s disease. Medical experts believe that “Alzheimer’s, like other common chronic diseases, develops as a result of multiple factors rather than a single cause.”⁴⁸ Risk factors include age, family history (in particular having a first-degree relative with Alzheimer’s disease), and the APOE-e4 gene. Traumatic brain injury can also increase the risk of developing certain forms of dementia.⁴⁹

⁴³ Minnesota State Demographic Center, “Demographic Considerations for Long-range and Strategic Planning,” (March 2016): 2-3, accessed December 4, 2018, https://mn.gov/admin/assets/demographic-considerations-planning-for-mn-leaders-msdc-march2016_tcm36-219453.pdf.

⁴⁴ Ibid, 4.

⁴⁵ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” 20-21.

⁴⁶ Ibid.

⁴⁷ U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, “Racial and Ethnic Disparities in Alzheimer’s Disease: A Literature Review. Evidence of Racial and Ethnic Disparities,” (2014), accessed December 11, 2018, <https://aspe.hhs.gov/report/racial-and-ethnic-disparities-alzheimers-disease-literature-review/evidence-racial-and-ethnic-disparities>.

⁴⁸ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” 11.

⁴⁹ APOE stands for apolipoprotein E.

Factors that might reduce the risk of cognitive decline include regular physical activity, healthy diet, and lifelong learning and cognitive training.^{50, 51}

Costs to the state and families

Alzheimer’s disease and other forms of dementia come at a great cost to individuals, communities, and the state. In 2017, researchers estimated that the total nationwide costs for paid care of people living with Alzheimer’s disease exceeded \$250 billion.⁵² According to the CDC, Medicare paid almost half of these costs. These costs are predicted to increase substantially, unless scientists discover how to prevent or cure Alzheimer’s disease and other dementias.

Family members and caregivers are often unpaid providers for long-term care for people with Alzheimer’s disease. According to data from the Behavioral Risk Factor Surveillance System (BRFSS), “about 25 percent of US adults aged 18 or older reported providing care or assistance to a person with a long-term illness or disability in the past 30 days. In 2018, the value of this unpaid caregiver activity is an estimated \$232 billion.”⁵³ A majority of caregivers are female, and nearly 10 percent of caregivers are providing care to someone with dementia. This number might be higher as the BRFSS question allows people to only name one chronic illness for the person they care for, and many people with dementia also have other chronic conditions. Caregiving brings with it emotional and physical stress: in a 2014 national survey, almost two-thirds of caregivers reported high or very high emotional stress due to caregiving (see Figure 4).⁵⁴

*[Caregivers share that] the fatigue they would feel from **never being able to get out of the house** because they could not leave their loved one alone caused them to get physically sick, become mentally drained, and in some cases develop a chronic illness of their own.*

–A Minnesota Board on Aging dementia grant recipient

⁵⁰ Ibid.

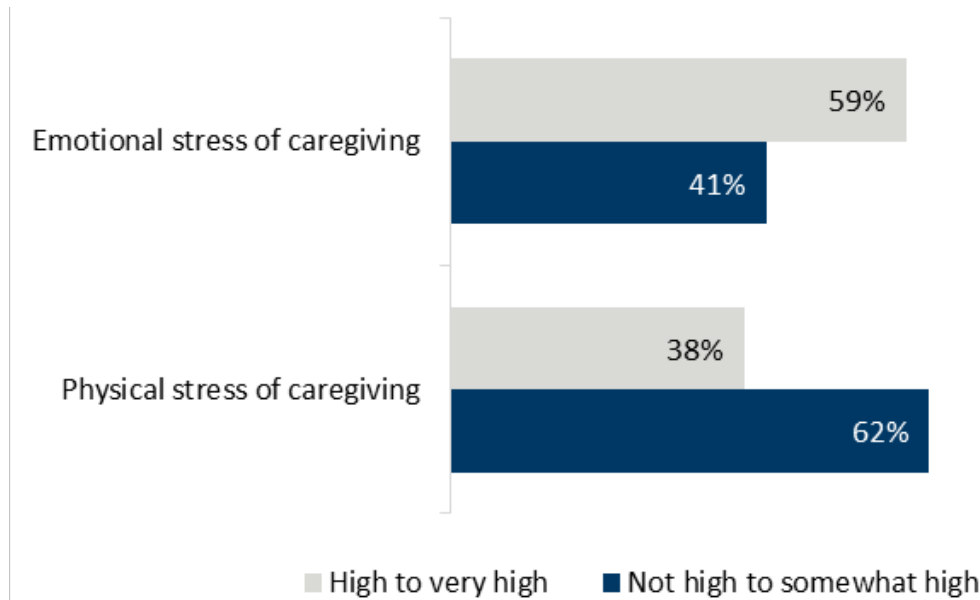
⁵¹ Terry Barclay, Michelle Barclay, and Michael Rosenbloom, “Living Well: A Guide for Persons with Mild Cognitive Impairment (MCI) and Early Dementia,” Alzheimer’s Association, accessed December 11, 2018, <https://www.actonalz.org/pdf/Living-Well.pdf>.

⁵² National Center for Chronic Disease Prevention and Health Promotion, “Alzheimer’s Disease: Promoting Health and Independence for an Aging Population at a Glance,” [accessed December 16, 2018](https://www.cdc.gov/chronicdisease/resources/publications/aag/alzheimers.htm) <https://www.cdc.gov/chronicdisease/resources/publications/aag/alzheimers.htm>.

⁵³ Ibid.

⁵⁴ Alzheimer’s Association, “2018 Alzheimer’s Disease Facts and Figures,” 35.

Figure 4: Proportion of caregivers of people with Alzheimer’s or other dementias who report high to very high emotional and physical stress due to caregiving.



Source: Alzheimer’s Association, 2018 Facts and Figures report.

Public awareness

Public awareness and knowledge of Alzheimer’s disease remains relatively low. A 2015 meta-analysis of 40 published studies suggests the general public has only fair to moderate knowledge and understanding of the disease. As the authors state, “the most common misperception was that dementia was a normal part of aging.” Moreover, they found that knowledge of Alzheimer’s was especially poor among certain racial and ethnic minority groups. Myths and stigma attached to the disease were also more common among these groups.⁵⁵

A 2018 Alzheimer’s disease and dementia awareness poll, conducted by the AARP, found that over 90 percent of American adults believe Alzheimer’s disease is a serious problem in our country today. Two-thirds of adults said they know someone who has had Alzheimer’s disease or dementia or another disease causing cognitive decline. Despite this high level of exposure to people living with dementia and other diseases affecting cognitive ability, many Americans lack knowledge about key characteristics of the disease. For instance, three-quarters of respondents incorrectly believe that memory loss is a normal and natural part of aging, and almost half of American adults incorrectly believe treatments are available to slow or stop the progression of Alzheimer’s disease.

⁵⁵ Suzanne Cahill, Maria Pierce, Perla Werner, Andrew Darley, and Andrea Bobersky, “A Systematic Review of the Public’s Knowledge and Understanding of Alzheimer’s Disease and Dementia.” *Alzheimer Disease & Associated Disorders* 29, no. 3 (2015): 255-275.

Cultural competence and responsiveness

As discussed in a previous section, Alzheimer’s disease affects racial and ethnic groups differently, both in terms of prevalence and public awareness. Discrimination, socioeconomic factors, genetics, and a lack of culturally competent providers all seem to be contributing factors to these inequalities.⁵⁶ As a result, some racial groups are less likely to be diagnosed, and less likely to receive quality care and long-term services and support.

According to the National Institute of Health, “Cultural competence is critical to reducing health disparities and improving access to high-quality health care that is respectful of and responsive to the needs of diverse patients. When developed and implemented as a framework, cultural competence enables systems, agencies, and groups of professionals to function effectively to understand the needs of groups accessing health information and health care—or participating in research—in an inclusive partnership where the provider and the user of the information meet on common ground.”⁵⁷

*A few days after one of our Dementia Friends training at a local bank, one of the tellers came up to our program director in tears. She said, “My grandmother has Alzheimer’s. I have not been able to communicate with her for some time. But when I heard the tips you gave for communicating with someone with Alzheimer’s, **I knew I had been doing it all wrong.** Now, I get down to eye level with my Grandmother and rather than try to get her to remember something, I let the conversation go whichever direction she likes. **Now I am able to have a satisfying conversation with her** without her becoming so defensive.”*

—A Minnesota Board on Aging dementia grant recipient

Residential services

There are currently no federal rules or regulations for assisted living facilities; instead, each state has its own specific regulations for assisted living. Centers for Medicare and Medicaid Services (CMS) oversees how states monitor abuse, neglect, and exploitation incidences of older people and people with disabilities who received Medicaid assisted living services. However, according to a U.S. Government Accountability Office (GAO) 2018 report, CMS’s guidance has been unclear and the GAO recommends that CMS improve its reporting requirements and guidance for states.⁵⁸

⁵⁶ U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, “Racial and Ethnic Disparities in Alzheimer’s Disease: A Literature Review. Evidence of Racial and Ethnic Disparities.”

⁵⁷ U.S. Department of Health and Human Services, National Institutes of Health, “Clear Communication,” accessed December 11, 2018, <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/cultural-respect>.

⁵⁸ U.S. Government Accountability Office, “Medicaid Assisted Living Services: Improved Federal Oversight of Beneficiary Health and Welfare is Needed,” (2018), accessed December 11, 2018, <https://www.gao.gov/assets/690/689302.pdf>.

2018 working group - project approach

Several factors influenced how the 2018 working group approached its legislative charge, including:

1. the increased participation of individuals directly impacted by Alzheimer's disease on the working group and various committees;
2. significant public attention to elder abuse in long-term care settings in Minnesota;
3. the working group's decision to direct the recommendations in the 2018 report at the state rather than the larger community;
4. a shared commitment to look at each element of the legislative charge through a lens of cultural responsiveness; and
5. a belief in the power of stories to influence change.

First, a large number of participants on the working group and the topical committees were directly impacted by Alzheimer's disease and other dementias. These members were passionate and vocal advocates for Minnesotans afflicted by dementia and their care partners. One message the working group retained from the 2011 report was the urgent need for "person-centered care." Central to this concept is that care providers are mindful of the unique cultural needs of individuals receiving care. This recognition of cultural differences led to an intentional conversation across the working group's committees regarding disparities, including a lack of relevant data to guide resource allocations as well as care and treatment decision-making.

As the working group developed its initial strategies for accomplishing its legislative assignment, members expressed a desire to seek input from other Minnesotans, even though public engagement was not a specific expectation. To that end, the working group implemented a "conversation-in-a-box" strategy for gaining broader perspectives on the topics for review and for stimulating informal community conversations about a disease that is often not talked about in constructive ways (see Appendix F for more details).

Second, the working group began its work while the state was attending to a crisis regarding the reporting and investigation of elder abuse complaints at long-term care settings. The media's examination of specific cases of maltreatment and state agencies' responses to the situation reminded the working group of the importance of their work. The crisis also challenged the working group to identify recommendations that would add a sense of urgency as well as value to the overall effort to better protect our vulnerable elders.

Third, recognizing the Minnesota Legislature requested this report, the working group intentionally developed recommendations that are directed at state entities rather than at a cross-section of entities involved in Alzheimer's disease issues in Minnesota. As such, this report contains fewer recommendations than the 2011 report. The working group also focused on recommendations that are actionable rather than aspirational.

Fourth, the working group approached their concern for equity and inclusion as integral to every step of their process. Central to the effort was the early work completed by the Cultural Responsiveness Committee, which provided a framework of values, an equity lens for analysis (see Appendix E), and reference resources for the other committees and the working group. Each step of recommendation development, synthesis, and final approval included careful consideration of those guiding values.

Finally, working group members often reflected on stories from the beginning of their first meeting to the end of their last meeting. They shared stories about loved ones lost to the disease, stories about the challenges and innovations in caring for people living with Alzheimer’s disease and other dementias, and stories imagining a truly dementia-friendly Minnesota. Stories became the central organizing theme of this report precisely because the working group recognized the power of stories to open hearts, change minds, and impact priorities.⁵⁹

A son’s story

My dad was a construction worker and farmer. He was a hard worker his whole life. When he was about 60 years old, he started noticing problems. **He never had memory issues, but his emotions and his skills started to disappear; he started not to be able to do things he used to be able to do.** He was going to the Mayo Clinic to figure out what to do but Mayo couldn’t diagnose him [and doctors] told him it was normal aging. He went to different providers, but no doctor would label anything.

Then all of sudden, after he had been married for 45 years, he left and moved up north. Without an explanation. He has six kids and it disrupted the whole family. Having worked in the field, I saw it coming, but everyone in the family had a different theory. **This created tons of conflict in our family. Eight years in, he finally got diagnosed with frontotemporal dementia. It took another four to five years for the family to accept it.** He moved back home but his brain wasn’t working right. He got aggressive even though he had never been aggressive in his life. He got violent with his wife and he didn’t want to be part of that which is why he had moved up north.

Now my dad is in a nursing home. He watches television five to six hours a day. But he still recognizes people. He sees people in the nursing home and remembers them. He remembers my kids. But his emotions are completely gone. He couldn’t put a nail in with a hammer. His mechanical ability is gone. About 12 years ago he came to build my house and had to ask me how to do things.

I hate to say it but I do not have hope. I see the negative. There are great people, but systematically I don’t have a lot of good to say. The pay [for care providers] is poor and the staffing pool is so weak. There are a lot of people who shouldn’t be in the field. There is no facility that wouldn’t hire someone without any experience. **It’s a huge problem—it’s a crisis, really.**

Overarching recommendations

When reflecting on the breadth of recommendations that emerged from their eight-month process, the working group felt compelled to include two overarching recommendations central to the state’s ability to prepare itself for Alzheimer’s disease and other dementias. If the state does not address these two broad recommendations, the state will not be able to respond successfully to many of the more specific recommendations.

⁵⁹ This report is enhanced by the personal stories of a variety of Minnesotans affected by Alzheimer’s disease or other dementias. With input from working group members, Management Analysis and Development collected these stories and quotes, which were used with permission and edited only for clarity or punctuation.

A. Comprehensive accountability for state actions on Alzheimer’s disease and other dementias

Key representatives from the Minnesota Legislature, the Minnesota Department of Human Services, the Minnesota Department of Health, and the Minnesota Board on Aging must determine how and where to centralize planning and coordination of all state efforts related to mitigating the impact of Alzheimer’s disease and other dementias in Minnesota.

Background

The Legislature asked for an updated set of recommendations to “prepare” Minnesota for Alzheimer’s disease and other dementias. Being prepared implies the state has a thoughtful, comprehensive strategy for addressing the impact of Alzheimer’s disease and other dementias on Minnesotans. It further implies Minnesotans can hold a state entity (or entities) accountable for accomplishing the desired results specified in the strategic plan.

While the working group considered the areas of concern the Legislature identified for review and developed recommendations within those areas, members were immediately struck by how fragmented previous state efforts “to prepare” the state have been. The working group noted fragmentation in:

- data collection efforts;
- public awareness messaging and campaigns;
- professional training expectations;
- regulatory enforcement; and
- licensing systems.

Intermittent working groups, no matter how well meaning and knowledgeable, will never be as capable at developing, executing, monitoring, and adapting a comprehensive plan as an entity within state government could be. In fact, a related sentiment was included in the 2011 report: “The working group believes Minnesota needs a much stronger and comprehensive statement on Alzheimer’s disease, which articulates the state’s commitment to policies and actions that support its citizens affected by the disease and prepares the state for the enormous increases in Alzheimer’s disease that lie ahead.” Concerted efforts to attack this problem every seven years armed with a collection of recommendations is no match for the array of challenges Minnesotans with this disease, and those trying to help them, now face on a daily basis.

B. Prioritize and invest in health care workforce development

The Minnesota Legislature should prioritize and invest in the development of the state’s long-term care workforce, with an emphasis on:

- attracting and retaining new and diverse people to health care professions with the largest shortages;
- continuous education and training in dementia care; and
- enhancing the portability/transferability of training, skills, and certifications.

The long-term care workforce encompasses those in medical professions, such as physicians, nurses and other allied health professionals, as well as direct care workers such as certified nursing assistants, home health aides, and personal care aides.

Background

As is true for the country as a whole, Minnesota faces a trifecta of workforce-related challenges: a modest growth *and* aging of its long-term care health workforce, a growth in the number of people living with dementia, and increased employment opportunities in less strenuous, less stressful, or better paid professions. Experts agree the situation is dire and only to get worse:

- By 2030, one in five Minnesotans are predicted to be over the age of 65, and 70 percent of Minnesotans 65 and older are expected to need long-term care services at some point.⁶⁰
- At the same time, Minnesota’s health workforce is aging,⁶¹ and wages in certain long-term care health professions are low, especially in direct care professions.
- In 2015, seven percent of full-time and 13 percent of part-time positions in direct care/support were vacant (compared to a rate of 3.6 percent for all occupations for the fourth quarter of 2015). In addition, the turnover rate in Minnesota for direct care/support positions was 36 percent.⁶²
- Some of the greatest needs are in rural areas and among traditionally underrepresented communities:
 - In rural areas, the median age of physicians is 56, and one-third of physicians are planning to leave the workforce within five years.⁶³
 - Over 80 percent of Minnesota’s physicians speak only English in their practice.⁶⁴

As we face these challenges to serve those living with Alzheimer’s disease and other dementias, it is time the Minnesota Legislature commits to a comprehensive approach to health care workforce development. Though the Legislature has invested in commendable efforts such as the Minnesota Health Care Loan Forgiveness program for health care professionals and the Primary Care Residency Expansion Grant program, these efforts fall short of what is truly needed given the current and projected workforce shortages. As the workforce need

⁶⁰ Minnesota State Demographic Center, “Demographic Considerations for Long-Range and Strategic Planning,” 3-4.

⁶¹ Ibid. See also: Department of Human Services, “Direct Care/Support Workforce Summit: Summary Report and Next Steps,” (2016), accessed January 9, 2019, <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-7271A-ENG>. The report’s appendices, including presentations by the Minnesota State Demographer and State Economist, can be found here: <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-7271C-ENG>.

⁶² Minnesota Department of Human Services, “Status of Long-Term Services and Supports.” Legislative report. August 2017, accessed December 16, 2018 https://mn.gov/dhs/assets/2017-08-long-term-services-supports_tcm1053-309107.pdf. For more information see “The National Core Indicators Staff Stability Survey” (a point-in-time survey conducted in December 2015), available at www.nationalcoreindicators.org/upload/coreindicators/2015_Staff_Stability_Survey_Report_V22.pdf.

⁶³ Teri Fritsma, “Supply and Demand of Health Care Workers in Minnesota,” (2017), accessed December 11, 2018, <http://www.health.state.mn.us/divs/orhpc/workforce/documents/pdf/2017mhasupplydemand.pdf>.

⁶⁴ Minnesota Department of Health, “Minnesota’s Physician Workforce, 2015: Highlights from the 2015 Physician Workforce Survey,” (2016), accessed December 11, 2018, <http://www.health.state.mn.us/divs/orhpc/workforce/phy/2016phy.pdf>.

continues to grow, increased transferability of training, skills, and certifications will allow for a more dynamic response to shortages.

A health care provider's story

To the best of my knowledge, **I am the only Spanish speaking neuropsychologist who sees dementia patients in Minnesota** as well as in Wisconsin, North and South Dakota, Iowa, Indiana, Michigan, Missouri, and Nebraska. I am also the only Native American neuropsychologist in Minnesota, which makes me a rare commodity in my field. Neuropsychological assessment is the gold standard for diagnosing dementia and currently the only way to identify mild cognitive impairment before it may develop into a dementia.

I do not advertise or market my services yet people still come from neighboring states to see me. This year, I had to stop taking new patients after my wait list extended out a year. **Patients complain they will die before their appointments... Sadly, some do.**

Minnesota is in desperate need of more neuropsychologists—especially those from diverse backgrounds—to address the needs of the state's aging and ever diversifying population. If Minnesota's goal is to be prepared for Alzheimer's disease and other dementias, the state must attract more qualified professionals, for instance by providing grants and subsidies for organizations or programs that train, hire, and retain neuropsychologists, particularly those from diverse backgrounds.

New stories for Minnesotans living with dementia

The working group organized its recommendations around five “stories” that envision a new reality for Minnesota’s response to Alzheimer’s disease and other dementias. Each story relates to a broader area of concern and what the working group believes the state should do to address those concerns.

The five stories are:

1. A data-rich state
2. Entrusting our care in dementia-capable professionals
3. All homes are safe homes
4. People are supported every step of the way
5. Living well with dementia

Each story consists of a vision, a set of values regarding cultural responsiveness necessary to successfully bring the vision into reality, and the working group’s specific recommendations for state action. Recommendations are numbered for reference, not to suggest prioritization or sequence.

A data-rich state

Vision

Careful analysis of accurate data from multiple vantage points should be foundational to all decisions regarding Alzheimer’s disease and other dementias, whether those decisions are medical, familial, or legislative. Data analysis tells us “what is” so that we can create a story about “what could be.” State government can shine a light on the needs of underserved populations, stimulate medical and care provider innovation, and encourage promising service partnerships. Minnesota’s dementia-related data is inadequate at a time when we need it to be extraordinary.

*The Minnesota Legislature needs to realize that **there are different types of dementia**. Research and support needs to be given to all types. It is also important that each person receive a proper, specific dementia diagnosis as the treatment for each is different. An emphasis on person-centered care is also important; **each person deserves to have the most specific, individual care plan** because we are all unique and special.*

–A caregiver

Value: asset-based approach to equity

When the state gathers data on Minnesotans that may have historically been underserved, it should approach that process considering the unique assets of those communities. For example, there are many different definitions of family that extend beyond biological relatives. When gathering information about informal

caregivers, expanding the definition of family may create a clearer picture of existing and potential networks of support.

Recommendations

In order to achieve the vision articulated above, the working group recommends the State of Minnesota do the following:

1. Install a recommendation tracking system

Designate an entity within state government to monitor the state's progress on implementing the working group's recommendations. This will end a reliance on external work group reviews, and will make monitoring accomplishments a part of the state's larger strategic plan for health and aging services.

Explanation

While the 2011 *Preparing Minnesota for Alzheimer's Disease Report* helped elevate innovations such as ACT on Alzheimer's® and the continued evolution of the Senior LinkAge Line as national models, no entity tracked the success or completion of the report's recommendations. This has made it difficult to determine whether Minnesota has achieved measurable, sustained progress. For example, the working group does not believe demonstrable progress has occurred in creating, developing, or leveraging statewide data sources to effectively document trends and opportunity gaps in dementia. To encourage a more comprehensive state response to Alzheimer's disease and other dementias, the working group recommends that a state entity track whether and how the entirety of the 2018 recommendations are implemented.

2. Improve overall quality, collection, and accessibility of the state's dementia-related data

Require more individual and coordinated efforts by the Minnesota Department of Health and the Minnesota Department of Human Services to improve the quality and availability of dementia-related data. Professionals involved in efforts that will positively impact the realities of this disease should have access to the data.

Explanation

The State of Minnesota has a variety of existing data sources that can and should provide better insight into the impact, needs, and opportunities related to dementia. However, this data is not centralized in one database or location, making it difficult to work with let alone influence improvement efforts. In addition, existing regional and statewide data sources could be expanded to include dementia-related questions to address key areas of interest among service providers, insurers, researchers, and state agencies. These could include examining patterns of care or the effects of quality improvement efforts.

More specifically, the state should:

Improve data quality

Minnesota's current dementia-related data does not reflect details such as age, race, ethnicity, or geographic region. Existing state resources must begin to reflect this important information, including data on recent

immigrant populations, Native American/American Indians, people living in rural areas, and individuals who identify as LGBTQ. This will allow the state to identify existing disparities and other variations in how these communities experience dementia over time.

Infrequent data collection poses challenges for researchers. The CDC's Healthy Aging Data Portal⁶⁵ allows access to BRFSS data, some of which relates to caregiving and cognitive decline. While helpful to Minnesota's researchers, new data on caregiving and cognitive decline is only collected every five years. This makes it difficult to identify trends. Additionally, while the BRFSS data allows researchers to document overall trends in disease prevalence and caregiving, the existing questions do not allow for more nuanced analyses. The MBA and MDH should work to identify the necessary resources and opportunities to include cognitive decline and caregiver modules in the BRFSS on a regular basis, including more refined questions on caregiving and cognitive decline. This would allow researchers and public health experts to better assess trends in cognitive decline and family caregiving in Minnesota.⁶⁶

Improve data collection

The state should also improve how it collects data on Alzheimer's disease and other dementias, in particular by acknowledging cultural approaches to the subject. This may include different modes and sources of data collection, such as using culturally diverse interviewers, offering surveys in multiple languages, and collecting more qualitative data. This more nuanced information will result in the more effective, targeted use of state data resources such as dedicated epidemiologist or research scientist to design, implement, and analyze new studies. Success will require a demonstrated respect of cultural and individual differences during data collection, data analysis, communication of results, and any resulting public health initiatives.

Improve data accessibility and connectivity

The Minnesota All-Payer Claims Database (APCD) can be a useful source of data to address questions about health care delivery system reform related to variations of cost, quality, utilization, and disease burden. The working group understands that access would require careful control. Secure access to this database by qualified researchers could produce information to inform policymakers and health care providers. They in turn could adjust how they provide and distribute resources to vulnerable individuals, their families, and communities. The state could improve accessibility by:

- Creating a process or mechanism for researchers and others to link individual or family caregiver clinical data with APCD records. This would link cost of care to effectiveness of care for vulnerable populations.

⁶⁵ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, "Healthy Aging Data," accessed December 11, 2018, <http://www.cdc.gov/aging/agingdata/index.html>.

⁶⁶ For example, the current BRFSS Caregiver Module only allows respondents to select one primary condition for the individual they care for. This is impractical, as those needing care often live with multiple chronic conditions simultaneously. In 2016, fewer than eight percent of caregivers stated they were caring for someone with dementia or other cognitive impairment as their main condition. Allowing for multiple responses would provide a more accurate reflection of the true number of people caring for people with dementia.

- Collaborate with the University of Minnesota, collaborate with another entity, or internally fund a process to address the following questions:
 - Building on recent reports commissioned by MDH, use the APCD to examine dementia trends by age group, geographic location, and sex.
 - Similarly, examine trends in the cost per person for individuals with dementia, as well as dementia-attributable spending (overall and by cost category), by geographic location and sex.

These collaborations could uncover ways to avoid diagnosis delays, avoid unnecessary hospitalizations, reduce psychotropic medication use, and provide other useful information to the medical community. Such data collaborations could also lead to earlier identification Alzheimer’s disease and other dementias, allowing families and caregivers to better plan for the future and for smoother care transitions.

3. Increase access to health care system and community data

The state should authorize the Minnesota Department of Health to obtain community data from Minnesota-based health care systems. This will allow them to develop and implement programs and policies that improve care and foster a nurturing, supportive environment for people with dementia and their caregivers.

Explanation

By providing place of death and usual residence, the death certificate indicates who was providing care at the time of death. Most deaths from Alzheimer’s disease occur in a nursing home or a long-term care facility. To track trends in the prevalence of Alzheimer’s disease’s, the state should analyze state- and county-level death certificate data available through MDH and the National Vital Statistics System through CDC WONDER.⁶⁷

At the national level, the percentage of people who died from Alzheimer’s disease complications in a medical facility declined from 14.7 percent in 1999 to 6.6 percent in 2014. In the same timeframe, the percentage who died at home increased from 13.9 percent to 24.9 percent. In Minnesota, the age-adjusted death rate from Alzheimer’s disease rose from 21.1 to 24.2 per 100,000 population between 1999 (1,083 deaths) and 2014 (1,623 deaths). This was a 14.5 percent increase in the death rate and a 50 percent increase in the total number of deaths.⁶⁸ The growing number of deaths with an underlying cause of Alzheimer’s disease, combined with a greater proportion of those deaths occurring at home, provides a strong indicator of the increased burden on family members and unpaid caregivers.

Analyzing this type of data along with data at the county level would allow policy and decision makers to target interventions and resources to counties and communities with the greatest need. For example, the MDH-administered State Health Improvement Program supports community self-assessments to help shape policy and environmental support within at-risk communities and populations.

⁶⁷ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, “CDC Wonder,” accessed December 11, 2018, <https://wonder.cdc.gov>.

⁶⁸ Christopher A. Taylor, Sujay F. Greenlund, Lisa C. McGuire, Hua Lu, and Janet B. Croft, “Deaths from Alzheimer’s Disease—United States, 1999-2014,” *Morbidity and Mortality Weekly Report* 66, no. 20 (2017): 521-526.

A researcher's story

As a behavioral neurologist, **I have been struck by the increased frequency of individuals receiving a diagnosis of Alzheimer's disease in their 40s, 50s, and early 60s.** Initially seen as a disease of the elderly, Alzheimer's disease is also the most common cause of young onset dementia. It affects individuals who are in the prime of their careers and still raising their teenage children, who may struggle to fathom the idea of having a parent with irreversible memory loss. These cases demonstrate **the broad reach of Alzheimer's disease, affecting people in the middle of life as well as those later in life.** Hearing these patients' stories, I am motivated to educate the greater medical community about the early presentations of Alzheimer's disease as well as obtain a better understanding of the mechanisms that drive these young onset presentations.

Research has shifted toward a more sophisticated and biological understanding of Alzheimer's disease. For many years, the disease has been defined based on vague criteria that take into account symptoms of cognitive decline and evidence for functional impairment. Consequently, **this diagnosis can be missed half the time in the primary care provider's office.** The development of imaging and spinal fluid biomarkers has enabled researchers as well as physicians to more effectively diagnose this disease and design clinical trials. Most recently, there has been a proposition about defining Alzheimer's disease in terms of these biomarkers based on the presence of amyloidosis, tau, and neurodegeneration (or ATN). Although this concept is currently reserved for the research setting, one can appreciate **a future where the classification of Alzheimer's disease and associated disorders may be staged in a way that resembles what is done with cancer.** Such an approach would allow for better definition of this disease in terms of its biology, thus facilitating early diagnosis as well as the validity of clinical trials. These are the **necessary first steps to take on the journey toward finding a cure for Alzheimer's disease.**

Entrusting our care in dementia-capable professionals

Vision

All Minnesotans benefit from a medical care community that is prepared, educated, and supported to diagnose, treat, and care for people with Alzheimer's disease and other dementias and their caregivers. This means providing person-centered care along the continuum of the disease, regardless of whether care takes place in a residential facility or at home. Patients need doctors who can be honest about someone's current and future capabilities and risks, and who can help family members and caregivers understand what to expect when living with and caring for someone affected by the disease. Minnesotans need doctors who can speak their languages and recognize their values. Minnesotans want to be treated with dignity and respect regardless of their individual background.

Values: authenticity and assets-based approach to equity

As the Legislature and state agencies consider the following recommendations to strengthen medical support for those living with Alzheimer's and their families and caregivers, the working group encourages them to show

authenticity, and to encourage others to do the same. Providers and people in positions of power must be open to not only hearing and learning about different needs but to addressing expressed concerns. They should use cultural humility as a way of showing a respectful attitude toward individuals of other cultures. They should show they have sought *and* fully heard the voice of the client, patient, and caregiver.

The Legislature should also be mindful that there are many variations of families and that caregiving can look different. A patient is an individual as well as a reflection of one's culture and family norms. The Legislature and state agencies should consider the needs of families and caregivers who may have different cultural norms and values related to Alzheimer's disease and other dementias, as well as families where the care structure is not a husband-and-wife team.

Recommendations

In order to achieve the vision articulated above, the working group recommends the State of Minnesota do the following:

4. Increase funding for clinical training at sites that serve populations with a high prevalence of dementia

The Minnesota Legislature should provide additional funding for clinical training at sites that serve populations with a high prevalence of dementia, such as nursing homes, assisted living facilities, adult day service providers, and home health agencies. They should either amend funding formulas for Medical Education and Research Costs (MERC) grants to include such sites or should appropriate additional funds.

Explanation

With an increasing number of Minnesotans in dementia care, Minnesota's long-term care workforce needs additional funding for clinical training. This need was already recognized by the 2011 Alzheimer's Disease Working Group, which noted that a transformation of health care systems "includes an immediate focus on beefing up the training that physicians, nurses and allied health professionals receive on dementia and its management."⁶⁹ Additionally, in a 2017 report to the Minnesota Legislature, MDH noted that "the MERC program has played a critical role in providing funding to clinical training sites across Minnesota...but it remains unclear whether recent efforts designed to incent more facilities to offer clinical training have had the desired impact, or whether there are other actions that Minnesota could take to ensure sufficient clinical training opportunities for the health care workforce of the future."⁷⁰ The 2018 working group echoes these concern and believes additional funding is needed for clinical training in dementia care.

⁶⁹ Alzheimer's Disease Working Group, "Preparing Minnesota for Alzheimer's: The Budgetary, Social and Personal Impacts," (2011): 28, accessed November 7, 2018, <https://www.leg.state.mn.us/docs/2011/mandated/110079.pdf>.

⁷⁰ Minnesota Department of Health, "Medical Education and Research Cost (MERC) Grant Distribution: Report to the Minnesota Legislature," (2017), accessed December 11, 2018, <https://www.leg.state.mn.us/docs/2017/mandated/170930.pdf>.

5. Make clinical training at nursing facilities eligible for MERC funding

The Minnesota Legislature should revise Minnesota Statutes 62J.692 to remove the exclusion of clinical training at nursing facilities from receiving MERC grants.

Explanation

The Minnesota Department of Health annually distributes MERC grants to providers of clinical medical education. These grants are used to fund a portion of the costs for clinical training of health professionals in Minnesota. MERC funds come from several sources, including cigarette tax revenue, federal Medicaid matching funds, and a carve-out of medical education funds from the Prepaid Medical Assistance Program.⁷¹ In 2007, the Minnesota Legislature excluded training at nursing facility settings from receiving MERC grants. Until this exclusion, clinical training in nursing homes received one to two percent of MERC distributions.

The medical education field needs additional support. Many health professional schools do not have an adequate number of clinical training sites, and few students from any health profession receive clinical training in long-term care settings for more than a few days. Only longer trainings provide the in-depth learning needed to effectively manage Alzheimer's disease and other dementias. The working group recommends the Legislature amend Minnesota Statutes to remove this restriction on MERC grants and to make these trainings, including training at nursing facilities on dementia care, eligible for funding.

6. Train health care professionals at Minnesota State Veterans Homes

The Minnesota Department of Veterans Affairs' (MDVA) State Veterans Homes (SVH) should partner with higher education institutions and other governmental organizations to help create a workforce prepared to provide long-term care services, including dementia care. The SVH are committed to providing comprehensive dementia training to improve quality of care, person-centered care, and resident satisfaction. This could be accomplished through comprehensive training of medical, dental, nursing, behavioral health, and other health care professional trainees.

Explanation

MDVA supports a philosophy of teaching and learning to improve resident quality of life and is in a unique position to provide health care professional training statewide through its five SVH.⁷² MDVA already has existing practices that support dementia care, in part because MDVA employees must receive dementia training under federal and state statutes. Some staff may also receive training from nationally-recognized dementia care programs and use these best practices to guide their care. The SVH also provide a medical model adult day

⁷¹ For more information on MERC grants, see <http://www.health.state.mn.us/divs/hpsc/hep/merc/index.html>.

⁷² The SVH are located in Fergus Falls, Hastings, Luverne, Minneapolis, and Silver Bay. Three additional SVH are proposed for Bemidji, Montevideo, and Preston.

health care program for veterans diagnosed with dementia on the Minneapolis Campus. This is one of three adult day health care programs on a SVH campus in the country.⁷³

This recommendation is intended to expand on the existing relationship between several health professional schools and the Minneapolis SVH. The recommendation would lead to an increase in the number of students trained at the SVH from these and other schools and enable new training opportunities at other SVH across the state. Expanding partnerships with higher education institutions and other governmental organizations would provide an opportunity to enhance the delivery of care services to SVH residents by involving health care professional trainees.

Trainees at SVH would benefit by observing staff modeling and participating in the dementia care programs. MDVA is open to strengthening the dementia care curriculum provided through its partnering organizations. In addition, a variety of post-graduate geriatrics-related training programs at the Minneapolis Veterans Medical Center, which is federally operated, would like to establish collaborative training opportunities with the SVH.

MDVA staff informed the working group that affiliation agreements with partner organizations are put in place at no cost. Nursing facilities are currently not eligible for MERC funding through MDH (but see the working group's recommendation on page 44). A decrease in general funds would adversely affect MDVA's ability to maintain and grow its health care professional training program and specifically utilize committed resources to ensure an enhanced level of dementia care training is provided to our staff and trainees.

7. Prioritize and incentivize reporting on Alzheimer's disease outcomes

The state, including the Minnesota Legislature and state agencies such as the Minnesota Department of Human Services and the Minnesota Department of Health, should prioritize and incentivize outcomes reporting on Alzheimer's disease by medical providers. Outcomes that should be reported include are not limited to the number of screenings/assessments, the number of people diagnosed with Alzheimer's disease and other dementias, and the number and types of referrals to other resources.

Explanation

Minnesota does not currently require providers to report any data related to dementia screening or diagnosis.⁷⁴ This recommendation would encourage the state and especially primary care doctors to be more mindful about early stages of Alzheimer's disease and other dementias. Outcomes reporting has already been explored by the state but not made a priority. It is time to make it a priority. This would also allow a better understanding of whether newly-diagnosed patients are being referred to other helpful resources in their communities, how those resources need to be enhanced, and how often health care providers connect patients to dementia resources.

⁷³ In 2016, the Minneapolis Adult Day Center and SVH Luverne received the Governor's Office Better Government Award for their Music and Memory programs.

⁷⁴ Some efforts were made in the past to incentivize providers to report such data but with very limited success.

8. Require training on cognitive impairment through health care licensing boards

The state should encourage Minnesota's health care professional licensing boards to require training on detecting, managing, and caring for patients with cognitive impairment as part of their continuing education requirements. This would include such boards as the Minnesota Board of Behavioral Health and Therapy, the Minnesota Board of Medical Practice, the Minnesota Board of Nursing, the Minnesota Board of Examiners for Nursing Home Administrators, the Minnesota Board of Psychology, and the Minnesota Board of Social Work.

Explanation

Requiring education on cognitive impairment in older adults will better prepare the health care workforce in Minnesota to address the growing, and often unmet, needs of the population with dementia. Currently, there is a lack of guidance for continuing medical education (CME) requirements for primary care physicians and there are no minimal requirements for credits related to dementia management. In comparison, physicians working at JCAHO-certified⁷⁵ comprehensive stroke centers must fulfill eight CMEs out of 30 on stroke training to maintain certification. The working group suggests adopting a similar approach for the broader Minnesota health care community.

9. Increase care providers' use of ACT on Alzheimer's® practice guidelines

State agencies and boards responsible for public health, such as the Minnesota Department of Health and the Minnesota Board of Medical Practice, should promote sharing and routine use of ACT on Alzheimer's® practice guidelines for the detection and management of cognitive impairment and dementia in primary and specialty care within all Minnesota health systems.

Explanation

Without incentives, physicians and providers are unlikely to use practice guidelines. It is also important to make the guidelines convenient for practitioners. To help with this, the working group recommends embedding ACT on Alzheimer's® guideline or similar best care practices⁷⁶ into electronic medical records. Embedding the guidelines in existing records will help primary care providers behave differently. The state could approach this change during negotiations for the state's reimbursement programs for special populations or through management services organizations. Embedding guidelines in electronic medical records may also help determine whether the guidelines are used or not.

⁷⁵ JCAHO stands for Joint Commission on Accreditation of Healthcare Organizations.

⁷⁶ For instance, see the Alzheimer's Association's "2018 Dementia Care Practice Recommendations," accessed January 9, 2019, <https://alz.org/getmedia/1a0020aa-0bfb-47ac-a545-1dd8a3ee1444/alzheimers-dementia-care-practice-recommendations>. This document was published as supplement to the February 2018 issue of *The Gerontologist*.

A long-term care provider's story

Over the past 20 years, I have had the honor of working within the long-term care industry in many different roles—dietary, maintenance, housekeeping, and management. Each role is a key ingredient in **providing the highest level of care, compassion, and empathy to individuals during their most difficult and their happiest moments.**

One of the most profound experiences (...) is when I am able to make a meaningful connection with an individual living with dementia. I have learned that **everyone, regardless where they are in their journey of aging, has a unique life story that needs to be celebrated and remembered.** These stories allow families, friends, and caregivers to connect on a personal level with the person living with dementia.

I am also completely amazed at all the individuals who give themselves tirelessly to help meet the needs of individuals under their care. **These employees are the unsung heroes and their desire and passion to provide the highest quality of care needs to be celebrated as well.** Each day that I work alongside these amazing individuals, I believe I need to show my unfading appreciation and amazement of their commitment to take care of individuals during their most difficult times and share in their happiest times. These employees deserve praise every day.

All homes are safe homes

Vision

Home. A place of safety when people feel most vulnerable. Where people are cared for, accepted, and celebrated for who they are. When Alzheimer's disease and other dementias begin to rob individuals of their abilities, their need for care and acceptance increases. At the same time the abilities of their informal network of caregivers are stretched, often adding to the suffering of the individual's family unit. Eventually families look for various support services that can ease the burden and keep diagnosed individuals safe and otherwise healthy in their homes. Finally, the support diagnosed individuals need progresses to the point where residential institutions often become necessary for the sake of everyone involved.

Widespread reports of safety and billing transparency issues in various kinds of residential institutions and home services program are a cause for deep concern. The working group expects the state to ensure all residential facilities and services are stable, safe, and affordable. No institution should care for people it is not equipped to care for. The state can act on the following expectations to ensure that all residences—no matter the location or type—will live up to expectations of “home.”

Value: openness to discussion

To help make this vision of home a reality, state agencies need to define patient rights and protections, interpret care standards centered on the needs of the individual, examine the meaning of “family,” and understand the burdens of caring for loved ones with Alzheimer's disease and other dementias. The working group encourages the state to proactively engage residents whose voices and experiences have historically received little attention

to help explore solutions and decision making processes. This will ensure the state achieves more meaningful outcomes for communities of color and indigenous people regarding their residential housing locations. The state has an opportunity to acknowledge, through constructive dialogue, the role that race and racism has played, and continues to play, in creating the dementia-related policies and procedures that provide services and support for some individual while denying them for others.

Recommendations

In order to achieve the vision articulated above, the working group recommends the State of Minnesota do the following:

10. Review, strengthen, and expand the rights of vulnerable adults in long-term care settings

The Minnesota Department of Human Services, the Minnesota Department of Health, and the Ombudsman Office for Long-Term Care should review, strengthen, and expand the rights of vulnerable adults living in long-term care settings and their families. Improvements should focus on care that is more person-centered and culturally responsive, and on enhancing criminal and civil enforcement when violations of people's rights occur.

Explanation

The applicable bills of rights are confusing, overlapping, and in some case missing key protections. Minnesota Statutes are inconsistent and have cross-references that are hard for individuals simply trying to exercise their rights to understand. Consumers are not broadly aware of these rights, may not have confidence exercising them, and can be concerned about retaliation. In some cases, families may have difficulty helping a vulnerable adult, such as a person living with dementia.

Specifically, the areas that should be reviewed for gaps include the Home Care Bill of Rights, the Health Care Bill of Rights for Residents of Supervised Living Facilities, the Minnesota Vulnerable Adult Act, the Assisted Living Addendum, the Hospice Bill of Rights, and the Patient Bill of Rights. Issues that could be addressed in this process include communication of maltreatment/abuse reports to the victim or their representative, electronic monitoring (cameras), retaliation, the right to appeal discharge, and deceptive marketing.

11. Clearly define Minnesota's dementia care standards across residential settings

The state should use existing resources to develop and adopt consistent baseline standards of person-centered care practices for individuals living with dementia in all types of long-term care facilities. Currently nursing homes must meet federal minimum standards for person-centered care that address issues related to care planning, staff training, therapeutic activities, and physical environments. However, other long-term settings such as housing with services and assisted living facilities are only required to disclose their philosophy and practice guidelines, and the government has no authority to enforce those self-disclosed standards. This inconsistency is confusing and sometimes harmful to Minnesotans.

Explanation

Direct care providers in residential settings help shape the daily lives of people with dementia and assist with all aspects of their physical care. Through their close interactions with people with dementia, direct care workers gain an in-depth knowledge of the individual with dementia, including their preferences, behaviors, and functioning. However, the standards that address how to care for individuals with dementia can vary greatly among care providers.

Multiple associations and organizations have created white papers, “best practices,” and standards of care about various residential care settings. MDH and DHS should leverage this work, existing federal standards, and MBA’s Cultural Consultants to define Minnesota’s care standards. This would ensure that all people living with dementia are in safe, appropriate, and respectful environments, no matter their facility type. These standards should include:

- Dementia training
- Staffing levels
- Sensitivity in approaches to egress (entry and exit) control
- Culturally- and LGBTQ-sensitive and respectful environments
- Physical environment best practices, including access to secured outdoor spaces
- Specialized therapeutic activities
- Specialized life enrichment programming
- When necessary, approach behavior modification through a practice of non-pharmacological interventions prior to/in preference to psychotropic medications.

While all the standards listed above are important, all employees who come into contact with people living with dementia absolutely need dementia training. Comprehensive dementia care training should include an evaluation of an individual worker’s competency, continuing education, portability for workers across employers, and minimum standards for trainers. The training curriculum should incorporate the principles of person-centered dementia care. This includes thorough knowledge of the person, their abilities and needs, and use of problem-solving approaches to care. Training should be culturally competent for both the provider and the care recipient. Finally, the working group expects Minnesotans will have easy access to these care standards whether the state has a primary or secondary role in creating a repository for this information.

12. Establish a license for assisted living facilities

The state should give the Minnesota Department of Health the authority to establish a license for assisted living settings. It should be consistent with existing standards of care for persons with dementia and aligned with regulations in other settings.

Explanation

Demands on the long-term care industry have drastically changed since the creation of the current system 20 years ago. The statutes regulating what consumers generally think of as “Assisted Living” and “Memory Care” (Housing with Services, Assisted Living, Special Care Units, and Home Care services) have become complex and confusing.

In January 2018, approximately 35,683 Minnesotans were living in Housing with Services facilities.⁷⁷ These settings are extremely popular because people perceive them as “flexing” to meet the changing needs of residents. In truth, they are less flexible than is often portrayed, and some families do not learn this until a care crisis happens. While home care providers are licensed, there is only a registry for assisted living facilities and no clarity for consumers as to what that title means.

Minnesota needs a license for assisted living settings. It should be consistent with existing standards of care for persons with dementia and aligned with regulations in other settings. This would guarantee a reasonable level of expectations for both consumers and facilities, and would make it clear to all parties when it is no longer appropriate for a resident to continue living in an Assisted Living facility. Assisted Living licensure should address:

- Staffing ratios, training, and licensure/duties
- Admission, public program acceptance, and eviction/discharge/termination guidelines
- Periodic assessments
- Procedures for transfers and transitions
- Dementia care/memory care standards
- Transparency of pricing, fees, deposits for services, and recourse
- Process for notice of facility closures
- Fire safety standards
- Dietary standards

Ultimately, the state must define who can be cared for in which settings, rather than allowing the marketplace to set the parameters.

13. Adopt a Minnesota Family and Medical Leave Act that includes “parent-in-law” in the definition of family members for which an employee can take unpaid leave

The Minnesota Legislature should adopt a Minnesota Family and Medical Leave Act that mirrors the federal Family and Medical Leave Act (FMLA), but includes a more expansive definition of “family” to include parent-in-law, following precedents from other states.

Explanation

Under the federal FMLA, Minnesota employees working for an employer of 50 or more employees can take up to 12 weeks of unpaid leave to care for a family member as defined by federal law. The FMLA restricts the definition of “family” to child, spouse, and parent. A parent-in-law is not included under the federal law despite

⁷⁷ Research Department, Minnesota House of Representatives, “Regulation of Health and Human Services Residential Facilities,” (2018), accessed December 16, 2018 <http://www.house.leg.state.mn.us/hrd/pubs/hhsfaci.pdf>.

a broad definition of parent, including foster parent and *in loco parentis*.⁷⁸ However, the FMLA allows states to expand the classes of persons for whom unpaid leave may be taken.⁷⁹ In contrast to some other states, such as California, Connecticut, and Oregon, Minnesota has not yet done so. This recommendation would have the Legislature adopt a Minnesota-specific Family and Medical Leave Act with a more expansive definition of “family” to include parent-in-law. This would then allow daughters-in-law and sons-in-law to take up to 12 weeks of unpaid leave to care for a parent-in-law.

The 2011 Alzheimer’s Disease Working Group also considered the need for a broader definition of “family” in the context of informal efforts to care for people with dementia. A broader definition has a strong cultural resonance with various ethnic communities across the state, who also often have a tradition of caring for loved ones and elders at home. The desire for a broader definition of family continued to resonate strongly with the 2018 Alzheimer’s Disease Working Group. Members discussed at length whether this recommendation is *enough* to demonstrate support for the valuable efforts of *all* individuals actively caring for people with dementia. Within these discussions, working group members also acknowledged the impact on employers if the definition were to be expanded.

The working group ultimately deemed this recommendation as an important, if small, first step to help Minnesotans help each other. The working group encourages the Legislature to take this small step and continue to have broad and vigorous discussion on a broader definition of family and caregiver with all Minnesotans.

*We would like the Legislature to know that **dementia is a personal issue as well as a societal issue**. People who have dementia should feel like they are part of the community and not feel that they have to hide because they are experiencing symptoms of dementia such as memory loss.*

–A family member of someone living with dementia

⁷⁸ U.S. Department of Labor, Wage and Hour Division, “Fact Sheet #28C: The definition of ‘parent’ as it applies to an individual who stood in loco parentis to an employee for FMLA ‘eldercare’ protections,” (July 2015), accessed December 11, 2018, <https://www.dol.gov/whd/regs/compliance/whdfs28C.pdf>.

⁷⁹ National Conference of State Legislatures, “State Family and Medical Leave Laws,” last updated July 19, 2016, <http://www.ncsl.org/research/labor-and-employment/state-family-and-medical-leave-laws.aspx>.

People are supported every step of the way

Vision

Alzheimer's disease is a chronic condition that can last more than a decade. With increasingly refined techniques to diagnose Alzheimer's disease at an early stage, more people will knowingly live with the disease when symptoms might be mild or non-existent. As the disease develops into Alzheimer's dementia, it affects memory, problem solving, relationships, and movement. During each stage, people living with the disease, their family and caregivers, and medical professionals have unique needs. For instance, many health care providers are (or feel) ill equipped to prepare patients for the disease progression. They might even be reluctant to provide information about a diagnosis of a dementia-related illness. Even individuals complaining of cognitive impairments may be afraid to learn of a specific diagnosis because of the unknown, and for family members, a diagnosis can be overwhelming. Moreover, relevant, supportive information may not exist in the language or format that is needed. All Minnesotans deserve the support of their entire community as they face the challenges of dealing with this disease.

Value: authenticity

True, meaningful support of people affected by Alzheimer's disease and other dementias is authentic support. This means we accept people where they are, whether they are an individual—or their family—who just received a diagnosis, or a provider or nurse caring for people with dementia. All Minnesotans must play an active role in the work of health equity and cultural responsiveness.

Authentic support also means providers and those in positions of power must be open not only to *hearing* and *learning* about different needs, but must also *address* expressed concerns. This is because cultural communities have many different norms related to how they view elders and dementia. Addressing expressed concerns shows they have sought *and* fully heard the voice of the client, patient, and caregiver.

A partner's story

One of the biggest impacts on my husband and myself is that we both worked hard to raise our family and put some savings away for our retirement, and then **just when our children were on their own and we were retired, my husband developed dementia** for which there is no cure. As a result, **we have been home bound for over ten years.**

Because my loved one is home bound, **I either need to stay home with him or hire someone to stay with him, which costs money, a lot of money.** If I am no longer able to care for him at home, I would have to put him in a care facility, which is very expensive.

These are conditions that young people—including my husband and I, at one time—don't usually give any thought to until it's too late. **What has happened to the talk about family compensation for the care of loved ones?** At this point, nothing gives me hope.

Recommendations

In order to achieve the vision articulated above, the working group recommends the State of Minnesota do the following:

14. Provide more information and counseling along the entire care continuum

The Minnesota Board on Aging should reevaluate the long-term care counseling process and the information provided through Senior LinkAge Line. Information should be provided in more consumer-friendly formats that supports patient and family decision making and general understanding of long-term care living options in Minnesota.

Explanation

The state plays an important role in educating the public on available medical resources and long-term care options for Alzheimer’s disease and other dementias. The Senior LinkAge Line is an existing state-supported telephone and online resource for this information, and is provided for free to all Minnesotans. Some people may prefer the Senior LinkAge Line to other resources because is accessible by email and phone. This is important for those who do not have access to or do not use a computer or the internet.

The working group believes the Senior LinkAge Line’s information can be expanded to include information along the entire care continuum, with links to existing dementia resources. For example, everyone can currently ask for a medical screening for dementia within a primary care setting, and the Senior LinkAge Line can play a role in sharing this information with families. The MinnesotaHelp.info site could also provide links not only to services providers, but to reliable, online educational resources on dementia.

15. Promote early detection and diagnosis and incentivize treatment of Alzheimer’s disease and other dementias as a chronic disease

The Minnesota Department of Health should reform health systems in Minnesota by promoting early detection and diagnosis of Alzheimer’s disease and other dementias. The Minnesota Department of Health should also incentivize the treatment of Alzheimer’s disease and other dementias as a chronic disease by keeping an up-to-date authoritative link on its website.

Explanation

Building onto its existing link for Alzheimer’s disease,⁸⁰ the Minnesota Department of Health should include on its website a portal for information with up-to-date links to keep the public and medical community informed on the latest research developments on Alzheimer’s disease and other dementias, such as evolving diagnostics. Having access to the most recent information will allow for new and appropriate person-centered early interventions to be developed.

⁸⁰ Minnesota Department of Health, “Alzheimer’s Disease and Related Dementias,” accessed December 11, 2018, <http://www.health.state.mn.us/divs/hpcd/alzheimer/>.

This website would include information on education and screening for Alzheimer’s disease and other dementias and modifiable risk factors, and how to include these into annual visit standards. Additionally, it would provide information about how to improve Minnesotans’ first experiences with a diagnosis through asset-based messaging and effective resource provision—placing their skills, networks, and community resources alongside their needs for care and support. Early diagnosis is crucial, but people often fear hearing a diagnosis of Alzheimer’s disease or another dementia. MDH’s website can provide resources for the public and the medical community to alleviate some of these fears.

Information that should be on the website includes:

- CDC information and links
- Medicare eligibility for cognitive assessment and coverage information and appropriate links
- CMS training
- Information on the need for cognitive assessments prior to Medicare eligibility

*Financial support from the state would allow professional experts to provide educational opportunities to **promote the importance of early diagnosis** and the development of end-of-life plans for medical care and family wills. These workshops could be made available free-of-charge for people without the means to hire personal consultants.*

–A caregiver

16. Improve regional networks of medical and community support

The state should actively support creative regional efforts to establish community dementia resource centers. These centers should work in partnership with each region’s medical community to create a better web of support for each resident needing services. This should include coordination with tribal communities.

Explanation

People with cognitive impairments are often embarrassed and confused by the loss of cognitive ability, and do not know where to turn for information or support. Partners and family members can feel equally overwhelmed. However, outside of the largest metropolitan areas of Minnesota, access to dementia-specific medical care specialists is very limited. Creating community dementia resource centers would promote dementia-friendly communities. These centers would provide in-person counseling in a non-medical setting. These centers would also engage the medical community, as doctors are often the first place many people go when symptoms develop.

The Minnesota Legislature should provide funding for the development of a statewide network of community dementia resource centers. It could provide grants to specific communities, possibly with technical support and assistance from academic health centers or health professional schools.

Implementation of this recommendation should include recognition of current and ongoing efforts such as:

- Public health departments, which play an important role in health promotion and disease prevention;
- Aging and Disability Resource Centers, which play a role in awareness and access to services; and
- The Alzheimer's Association.

Living well with dementia

Vision

While the disease itself cannot be prevented, Minnesotans impacted by Alzheimer's disease and other dementias face other significant and preventable risks, such as financial exploitation, consumer fraud, and unsafe driving. To protect and keep everyone safe, Minnesota needs to increase awareness of the disease; reduce stigma related to the disease; and develop standards and guidance regarding safety issues which can help mitigate some of the non-medical risks.

These efforts are especially important as the number of people living with Alzheimer's disease and other dementias increases. Greater awareness and guidance opens up conversations among family members and health care providers about the shame that can go along with cognitive decline and the resulting safety concerns. This is often not an easy topic for people to talk about, and people might feel they will lose control if they reveal their dementia diagnosis. However, clear standards and guidelines can help create a safe space within which to have these conversations. They can allow people living with Alzheimer's disease and other dementias, and their caregivers, to feel more in control and live more independently.

Value: assets-based approach to equity and diversity

When considering how to mitigate the risks faced by people living with Alzheimer's disease and other dementias, it is important to acknowledge and accept that there are many variations of families, caregiving, and cultural norms related to elders and dementia. A patient is an individual as well as a reflection of one's culture and family norms. As the Legislature considers how to mitigate risks, members should consider the needs of families and caregivers who may have different cultural norms and values related to Alzheimer's disease and other dementias. An equitable solution may mean that different groups need different things, rather than a one-size-fits-all approach.

An MBA dementia grant recipient's story

As the dementia awareness coordinator at our organization, I help raise awareness of dementia, for instance through Dementia Friends sessions. As an organization, we are committed to encouraging and supporting older adults to have good, high-quality lives. **We serve people who have traditionally been underserved. There is a lot of need, but people also face many barriers and disparities.** In privately paid facilities, for instance, there is discrimination and stigma related to certain varieties of dementia. People from underserved communities can also have less support from friends and families to help them navigate services. And people with early-onset dementia often do not have the same support system, and don't feel comfortable in long-term care facilities that serve older adults.

I also focus on mental health and chemical dependency and the interplay with dementia. People with chemical dependency or brain injury can experience early-onset dementia. I've seen people in their forties experience dementia; these are unique but very challenging situations. **I've found there is a lot of misunderstanding of mental health issues and dementia; we need to understand people can have both at the same time.** For example, I know a patient who got kicked out of a shelter because of what was thought to be a mental health issue, when in fact he was not able to articulate his needs due to dementia. **We need to equip providers, people in the community, and advocates to know what this interplay between mental health and dementia might look like.**

The Legislature should know that there is a rise in other varieties of dementia, not just Alzheimer's disease. Dementia is often equated with Alzheimer's disease, but there are over eighty varieties of dementia and they are not the same. Memory care focuses on older adults but it's important that legislators know about the services available and needed for lesser known dementias.

It gives me hope that people with memory loss can live good, healthy lives. Our organization has lots of programs in place to let people live in the community. **That's where people want to be: in their home and in their community.** It also gives me hope that there are forward-thinking visionaries in our state, who understand the many socio-economic challenges that people face but are looking at the big picture.

Recommendations

In order to achieve the vision articulated above, the working group recommends the State of Minnesota do the following:

17. Coordinate a structured awareness campaign

The Minnesota Legislature should support a collaboratively led, coordinated, statewide, coordinated public awareness campaign of Alzheimer's disease and other dementias. This campaign should help reduce stigma, offer a balanced perspective of risks and treatment possibilities, and share how people adapt to and "live well" with a diagnosis of Alzheimer's disease or other dementia.

Explanation

Minnesota does not currently have a collaboratively led, coordinated, statewide public awareness campaign for memory impairment. To reduce stigma, an awareness campaign could offer a balanced perspective that includes how to mitigate risk factors, adapt well to a diagnosis of Alzheimer's disease and other dementias, and easily access information. Stigma and fear of a terminal diagnosis leads many individuals to not acknowledge they are experiencing memory issues. This results in valuable time lost to maintain a good quality of life. Despite existing community resources in Minnesota, individuals, families, professionals, and communities struggle to obtain evidence-based education about memory impairment, ways to reduce modifiable risk factors, and connections to existing support services.

The content of a statewide messaging campaign could include:

- Information about aging normally versus aging abnormally.
- Information to enhance medical professionals' awareness of how to connect to non-medical community supports.
- Connections to existing resources, such as the MBA's Cultural Consultants, the Alzheimer's Association, Senior LinkAge Line, and mnhelp.info.
- Information about the MBA's dementia grants.
- Connections to other statewide public health awareness campaigns; this would enhance consistent messaging and understanding of how Alzheimer's disease and other dementias fit into other chronic disease and mental health work.

Steps toward this statewide messaging campaign could include:

- Designating an entity to collaboratively develop statewide language based on evidence and promising practices. This should allow for local customization for cultural traditions and understanding.
- Empowering the designee to develop a strategy to implement shared language across stakeholders in Minnesota.
- Thoughtfully and intentionally acknowledging the experiences of those who have not had the experience of "living well" with dementia.
- Providing community communications, messaging, and access to valid resources in multiple formats to ensure every community member can access them regardless of their computer capabilities or language. Specific ideas include providing information in local newspapers, tribal newspapers, radio stations, and religious communications.

*The financial support we receive from the State of Minnesota to make our communities "Dementia Friendly" is paying off. **Dementia Friends training is making an impact** with people who may or may not have had direct experience with someone living with Alzheimer's. This is making it easier for people with dementia and their caregivers to go to businesses or community events and **experience a normal life while living in their own home as long as safely possible.***

–A Minnesota Board on Aging dementia grant recipient

18. Develop guidance for the medical community regarding specific safety risks faced by persons living with Alzheimer’s disease and their families.

The Minnesota Department of Public Safety, the Minnesota Department of Health, and other relevant state agencies should convene a group of dementia experts, dementia clinicians and other pertinent community stakeholders to develop standards around risks and safety and Alzheimer’s disease and other dementias, including but not limited to driving and firearms and to recommend an implementation strategy that could include dissemination through ACT on Alzheimer’s[®] practice guidelines, continuing medical education standards, or other regulatory or statutory changes.

Explanation

Few Minnesota agencies have guidelines around general safety and people with Alzheimer’s disease and other dementias.⁸¹ While there is guidance for driving and dementia, dissemination to the general public and to clinicians could be improved. There is no guidance on firearm safety and dementia, which mirrors the national state of affairs.⁸² The Minnesota Department of Commerce has recommendations on protecting vulnerable adults from fraud and financial exploitation.⁸³

These are difficult and sensitive topics to discuss. People living with Alzheimer’s disease or other dementias might fear that discussing these topics will lead to limitations on their ability to live well. Additionally, a lack of information and guidance can lead to unsafe situations on the roads or in people’s homes and can pose a public health risk. Without clear state guidelines, patients, their families, and providers are put at risk. In some cases, the lack of confidence in navigating these safety concerns may discourage physicians from communicating a diagnosis of Alzheimer’s disease or other dementia to the patient and family. Guidance from the state can provide this much-needed support to physicians and other medical providers. The working group discussed how concerns of both the medical community and people affected by the disease need to be taken into account when state agencies develop these guidelines.

Other topics for state agencies to consider are home safety, traveling, medication supervision, financial supervision, and consumer fraud. Agencies might also look at what other states are doing to reduce risks and

⁸¹ One example is a publication by the Minnesota Department of Public Safety (DPS) called “Medical Conditions and Your Driver’s License,” (April, 2013), accessed December 19, 2018, https://dps.mn.gov/divisions/dvs/forms-documents/Documents/MedicalConditions_and_YourLicense.pdf. At the time of writing, the Office of Traffic Safety, a division within DPS, had issued a request for proposals for a grant to a non-profit or governmental entity to “implement traffic safety activities with the objective of reducing crashes, injuries and deaths involving older drivers.” <https://dps.mn.gov/divisions/ots/older-drivers/Pages/default.aspx>, accessed December 19, 2018.

⁸² Melissa Bailey, “Doctors Need to Talk to Families about Guns and Dementia,” *New York Times*, October 9, 2018, <https://www.nytimes.com/2018/10/09/well/live/doctors-need-to-talk-to-families-about-guns-and-dementia.html?action=click&module=Discovery&pgtype=Homepage>.

⁸³ Minnesota Department of Commerce, “Minnesota Department of Commerce Guidance on Privacy Laws and the Reporting of Financial Abuse of Older Adults,” accessed December 19, 2018, <https://mn.gov/commerce/industries/financial-institutions/privacy-laws-and-reporting-financial-abuse.jsp>.

increase safety, including states that provide immunity from Health Insurance Portability and Accountability Act violations.

Some existing resources that could provide a starting point include:

- The Alzheimer’s Association, which has a number of resources including:
 - A publication on firearm safety.⁸⁴
 - A safety assessment checklist, which includes questions on driving and firearms.⁸⁵
 - A brochure on several risk factors and how to stay safe.⁸⁶
- The U.S. Department of Veterans Affairs 2016 recommendations for dementia care in the Veterans Health Administration’s health care system (see especially recommendations 34 and 35 in their report).⁸⁷
- The University of California–Davis’s Violence Prevention Research Program, which includes advice for providers on how to counsel patients on firearms.⁸⁸
- HealthPartners’ ongoing work on a safety checklist for people with Alzheimer’s disease.

⁸⁴ Alzheimer’s Association, “Firearm Safety,” (July 2018), accessed December 11, 2018, <https://www.alz.org/media/Documents/alzheimers-dementia-firearm-safety-ts.pdf>.

⁸⁵ Alzheimer’s Association, “Safety Assessment,” accessed December 11, 2018, <https://www.alz.org/careplanning/downloads/safety-assess-checklist.pdf>.

⁸⁶ Alzheimer’s Association, “Staying Safe: Steps to Take for a Person with Dementia” (December 2016), accessed December 11, 2018, https://www.alz.org/national/documents/brochure_stayingsafe.pdf.

⁸⁷ U.S. Department of Veterans Affairs, “VHA Dementia Steering Committee Recommendations for Dementia Care in the VHA Health Care System,” (2016), accessed December 11, 2018, https://www.va.gov/GERIATRICS/docs/VHA_DSC_RECOMMENDATIONS_SEPT_2016_9-12-16.pdf.

⁸⁸ University of California, Davis, Violence Prevention Health Program, “What You Can Do to Stop Firearm Violence,” accessed December 19, 2018, <https://www.ucdmc.ucdavis.edu/vprp/WYCD.html>.

A daughter's story

Our mom was diagnosed with Lewy Body Dementia at the Mayo Clinic when she was 81 years old. She had just retired at the age of 80 from a well-known Minnesota resort, where she ran the laundry. As she was being assessed, we witnessed her struggle with the questions and knew a dementia diagnosis was imminent. While we were in the doctor's office, when she received the news, her first question was, "Is it terminal?" **We knew that our roles would be reversed and it was our job to make sure she knew she was loved and cared for always.**

My sister, brother, daughter, and I helped mom every weekend and weekdays as she needed. We spent many weekends and nights with her. Other family checked in with her but as mom needed more help it was just her kids and granddaughter who took care of her. **Many family and friends were nervous to visit because they had a hard time watching mom change.** We as a family were able to keep mom at home for five years with mainly our family's help and a little home care during the week. After five years, mom needed 24-hour assistance and we could not provide that with family and informal supports. Mom moved to a memory care unit in September and passed away in November of the same year.

Our mom was our hero. Not because she raised three children by herself. Not because she ran a gas station and oil delivery by herself and not because she worked until she was 80 years old. **It is because she tried every day to live with a disease that took over her body and her mind.** She worked so hard every day to keep her life and mind together. She kept her sense of humor until the end. We are so proud of her and love her so much. We miss her every day.

Appendix A: 2018 Alzheimer’s Disease Working Group roster

Table 1: 2018 Alzheimer's Disease Working Group roster

Category of appointee	Name
Caregiver of person with Alzheimer’s Disease	Eric John Linn, concerned citizen
Person living with diagnosis	Darrell Gene Foss, retired CPA, person living with Mild Cognitive Impairment diagnosis
Nursing facility or senior housing representative who is affiliated with LeadingAge MN	Jean Marie Nelson, RN, Knute Nelson
Nursing facility or senior housing representative who is affiliated with Care Providers of Minnesota	Dan Pakonen, Owner/Treasurer, HHLP, Inc.
Neuropsychologist	Terry R. Barclay, PhD, LP, Clinical Director, Neuropsychology Center for Memory and Aging, HealthPartners
Researcher	Joseph E. Gaugler, PhD, Robert L. Kane Endowed Chair in Long-Term Care and Aging, School of Public Health, University of Minnesota
Community-based organization	Amanda Mithun, MS, LAMFT, Lakewood Health System Dorothea Harris, LICSW, Volunteers of America Minnesota/Wisconsin
Neurologist	Dr. Michael H. Rosenbloom, Director, Center for Memory and Aging, HealthPartners
Geriatrician	Edward Ratner, MD, Associate Director, Education and Evaluation, Minneapolis Veterans Administration Medical Center
Home care or adult day services rep. affiliated with LeadingAge MN	Peggy Gaard, Augustana Care
MDH commissioner designee	Mary Manning, Division Director, Health Promotion Chronic Disease, MDH

Category of appointee	Name
Representative of the Alzheimer's Association	Heidi Haley-Franklin, MSW, LICSW, Alzheimer's Association of Minnesota-North Dakota
State Ombudsperson for Long-Term Care	Cheryl Hennen, State Ombudsman for Long-Term Care
DHS commissioner designee	Gretchen Ulbee, Manager, Special Needs Purchasing, DHS
MBA member	Sherrie Pugh, member, Minnesota Board on Aging
MBA executive director, ex-officio member	Kari Benson

Appendix B: Committee rosters

Working Group members are not listed within their committee assignments.

Table 2: Assessment of Trends and Disparities Committee

Name	Title/Affiliation
Steve Waring, DVM, PhD	Research Scientist, Division of Research, Essentia Institute of Rural Health
Kirsten Hall Long, PhD	Principal and Senior Health Economist at K. Long Consulting, LLC
John Selstad	Lead MBA staff for 2011 Legislative report
Don Bishop, PhD	Director, Center for Health Promotion, Minnesota Department of Health
Rachel Zmora, MPH	PhD student, University of Minnesota School of Public Health
Colleen Peterson, MS	PhD student, University of Minnesota School of Public Health
Richard Olson	Caregiver

Table 3: Cultural Responsiveness Committee

Name	Title/Affiliation
Lisa Albrecht, PhD	Retired professor, Social Justice, University of Minnesota and caregiver
Clarence Jones, MEd	Community Engagement Consultant
Nancy Lee	Staff, Minnesota Board on Aging
Melissa Castro, PsyD, LP, ABPP	Clinical Neuropsychologist, Minneapolis Clinic of Neurology
Tai Sims, PhD(c), DNP, MSN, RN, PHN	Associate Professor, School of Nursing, Minnesota State University, Mankato
James Sorbel	Alzheimer’s Association Congressional Ambassador (Fifth Congressional District)and Young Champion
Monisha Washington	Community Health Worker Project Coordinator, Volunteers of America Minnesota
Grant Watkins	Volunteer Services, Wilder Center for Aging
Robbin Frazier	Director of Diversity and Inclusion, Alzheimer’s Association–Minnesota and North Dakota
Luisa Vintimilla	Not available
Lindsay Juricek	Carver County

Table 4: Diagnosis, Treatment, and Professional Development Committee

Name	Title/Affiliation
Katie Roberg	Manager of Programs and Education, Alzheimer’s Association–Minnesota and North Dakota
Cheryl Smith, JD	Director of Education, Care Providers of Minnesota
Deborah Richman, BS	Executive Manager, Becketwood Cooperative
Patrick Zook, MD	Retired family physician, President, Stearns Benton Medical Society
Cally Vinz	Not available
Fang Yu, PhD, RN, GNP-BC, FGSA, FAAN	Professor, Center for Aging Science and Care Innovation, Center of Aging, University of Minnesota School of Nursing
Mary Margaret Lehmann	Caregiver
Rebecca Sash	Arrowhead Regional Development Commission

Table 5: Public Awareness and Risk Reduction Committee

Name	Title/Affiliation
Clarissa Dumdei, ANP/GNP	Avera Health
Kathleen Dempsey	Not available
Trevor Wichner, MS	Housing Administrator, Knute Nelson
Pennie Page	Not available
Linda Bane Frizzell, PhD, MS	Faculty, University of Minnesota School of Public Health
Lori Vrolson	Executive Director, Central MN Council on Aging
Angela Lunde, MA	Education Manager, Associate, Neurology Mayo Clinic
Carla Zbacnik	VP Marketing, Alzheimer’s Association–Minnesota and North Dakota Chapter
Kelly Hugunin	Former caregiver
Robyn Birkeland, PhD	Study Counselor, Families and Long Term Care Projects, University of Minnesota
PJ Mitchell	Public Policy Analyst, Medica
Jenny West	Community Educator, FamilyMeans
Cathy Griffin	MDH
Ann Brombach	Not available
Linda Giersdorf	Executive Director, Minnesota River Area Agency on Aging
Lori Paulson	Senior Advocate, City of Winona

Name	Title/Affiliation
John Riley McCarten	Geriatric Research, Education, and Clinical Centers, Minneapolis VA Medical Center and Department of Neurology, University of Minnesota Medical School

Table 6: Residential Services Committee

Name	Title/Affiliation
Aimee Rumpza	Program Administrator, Aging and Adult Services, DHS
Sue Boyd	Elim Care
Sandi Lubrant	Citizen Advocate
Beth McMullen	Vice President, Government Affairs, Alzheimer’s Association Minnesota-North Dakota
Susan Eckstrom	Executive Director, Rakhma
Karen Parks	Caregiver
Mary Absolon	Health Survey and Compliance Manager, Minnesota Department of Health
Sarah Keenan	Chief Clinical Officer/President Integrated Care Bluestone Physician Services
Heather Davila, MPA	University of Minnesota
Michelle Demcho	Lakeview Ranch
Anne Sinotte	Family member, caregiver
Tamara Statz, MA, LMFT	Study Counselor, University of Minnesota
Dan Tupy	Regional Ombudsman for Long-Term Care

Appendix C: Special thanks

The working group wishes to thank the following people who shared their time and expertise as conversation facilitators and guest speakers at various working group meetings:

- Venoreen Boatswain-Browne
- Yoli Chambers, Centro Tyrone Guzman
- Glenda Duhamel, Northwoods Caregivers, Bemidji
- Farhiya Farah, St. Mary's University
- Kathryn Gonzalez, Northwoods Caregivers, Bemidji
- Laura Hood, Aging Service Director, City of St. Cloud
- Danica Robson, Land of the Dancing Sky Area Agency on Aging
- Dr. Ronald Peterson, Mayo Clinic Alzheimer's Disease Research Center
- Dr. George Schoepfoerster, Genevive
- Sara Chute, Center for Health Equity, Minnesota Department of Health
- Bruce Thao, Center for Health Equity, Minnesota Department of Health

Appendix D: Report development process

Project timeline

The overall timeline for the project was September 1, 2017, through January 31, 2019.

The project was conducted in two phases. During the first phase, September 1, 2017, through June 30, 2018, the working group met three times (on January 8, April 24, and June 28). In addition, the five topic-specific committees conducted three to five meetings each. Phase two occurred between July 1, 2018, and January 31, 2019, during which the working group met twice (on August 14 and October 28) to finalize the recommendations and report.

Specific roles

Working group

The Minnesota Board on Aging (MBA) appointed the working group members per the direction of the 2017 Minnesota Legislature. The working group reviewed the issues outlined in the legislative charge to develop findings and recommendations. To enable more in-depth consideration of these issues, the working group organized five topic-specific committees. Each committee considered new data, expert perspectives, and the experience of citizens directly impacted by Alzheimer's disease and other dementias. They generated an initial set of recommendations that the working group then further refined. All groups used a consensus process to decide on final recommendations.

Committees

Committee topics were determined in accordance with legislative requirements for the final report. The working group members nominated committee members. Each committee consisted of between five and 15 people. Committees gathered and synthesized information to present to the working group in the form of tentative recommendations for the working group's consideration. Committees included:

- Assessment of Trends and Disparities
- Diagnosis, Treatment, and Professional Development
- Residential Services
- Cultural Responsiveness
- Public Awareness and Risk Reduction

All stakeholder working group meetings and committee meetings were open to the public.

Management Analysis and Development

The Minnesota Board on Aging contracted with Minnesota Management and Budget's Management Analysis and Development (MAD) to provide consulting services. MAD consultants provided planning, coordination,

facilitation, and overall support to the working group and committees. Using the recommendations of the working group and input from a number of working group and committee members, MAD consultants developed the final legislative report. MAD consultants strove for a participatory process with public engagement opportunities throughout the process.

Minnesota Board on Aging

The MBA's responsibilities included facilitating meeting logistics and submission of the working group's report to the Governor and chairs and ranking minority members of the legislative committees with jurisdiction over health care.

Appendix E: Equity lens for analysis and key terminology

The Cultural Responsiveness Committee developed the following questions for the committees and working group to use throughout their work to develop recommendations and the final report to the Legislature.

Equity lens questions for analysis

- What groups are most impacted or marginalized in relation to this policy/program/issue?
- Who is most affected by the policy/issue program? Who is included/excluded from this policy/program/issue?
 - What needs to change in the proposed model that takes into consideration the social, economic, and political structures that impact the desired outcome?
- What are the biomedical and public health barriers for:
 - People and families accessing services?
 - Providers to providing culturally responsive care?
 - Creating a system/policy that leads to more equitable outcomes?
 - Participation of community groups?
- Who is at the table for decision making related to this topic? Who is missing?
 - How can decision making be shared with rather than just informed by the communities impacted?
 - Who is paid/not paid to be at the table? How do we create structures to compensate communities for their time and engagement in this work? Pay community members and cultural consultants to participate and share knowledge.
 - Who are the allies to help work with different communities on this policy/program/issue?

The committee also developed a list of key terms, which can be found on the Minnesota Board on Aging's website.⁸⁹

⁸⁹ The Cultural Responsiveness' full report to the working group, including key terms, can be found here: http://www.mnaging.net/en/Advocate/~media/MNAging/Docs/Advocate/ADWG/ADWG_CR_Recommendations.ashx, accessed December 19, 2018.

Appendix F: Conversation-in-a-box summary

Description

As the working group developed its initial strategies for accomplishing its legislative assignment, members expressed a desire to seek input from other Minnesotans, even though public engagement was not a specific expectation. To that end, the working group implemented a “conversation-in-a-box” strategy for gaining broader perspectives on the topics for review and for stimulating informal community conversations about a disease that is often not talked about in constructive ways. Each of the standing committees compiled and reviewed the input from the participants in these conversations as they developed their initial recommendations.

The concept was simple: Provide a facilitator guide and note-taking form. Put it in an easy to use package along with information about online options and a facilitator thank-you note. Use the committee and various existing events such as the Alzheimer’s Association’s Meeting of the Minds conference for distributing the materials to any group interested in having a conversation about dementia and sending in their notes.

Topics for which input was requested included:

- **Public awareness:** Attending to the public’s knowledge gaps and community support systems.
- **Diagnosis and treatment:** Considering the health care experience from doctor skills to cost of treatment.
- **Residential services:** Acknowledging the impact of cost to families as well as the impact of regulations and licensing gaps.
- **Health equity:** Supporting all Minnesotans faced with Alzheimer’s disease and other dementias in ways that are culturally appropriate.

The total number of boxes distributed: approximately 170.

Number of participants in conversations submitted: 116.

Participant backgrounds

- Geriatrics nursing staff in rural Minnesota
- Adult children and spousal care partner group
- Home- and community-based agencies that provide support and informal caregivers
- Volunteers working with “dementia families”
- Alzheimer’s Association chapter staff
- Researchers
- People with early-stage Alzheimer’s disease and MCI

Public awareness

Critical themes identified by the working group

- How do you get more people to say “I do have memory impairment and how can you help me?” The environment does not feel safe; there is still fear and stigma.
- Talk about it more. Make it a common theme. Treat it like it’s a fact: x percent of you in our community will have this.
- Acknowledging Alzheimer’s disease to find preventive measures early on. So you change your habits and accept that and then support one another.
- Educate them more, and make sure we have a voice. We have the well-being of the people to consider.

How could Minnesota’s state and local government influence more positive outcomes related to public awareness?⁹⁰

- Change social mindset/culture to focus on dementia as a family situation, not an individual disease.
- Make sure resources are connected.
- More research in our state does not mean medicine, but also lifestyle changes and living well.
- More awareness on “age related memory loss, and warning signs.”
- Learn from the recovery/addiction field. Treatment must be much more holistic and inclusive.
- Provide funding for:
 - Continued support of ACT communities and provide funding to keep the current ones going.
 - Education: public service announcements.
 - Education grants to students pursuing a health care career.
 - Increase wage reimbursement rates for nursing home workers.
 - Programs that help delay the disease such as nutrition and exercise.
 - Increase funding to health care homes to treat all patients, not just those with complex chronic conditions.
 - Expand broadband access to rural areas for telehealth connectivity.
 - Overhaul the FMLA program.
 - Increase the current homemaking service reimbursement rate.
 - Lighten restrictions when providing funding for new initiatives.
 - Alleviate some of the cost by providing more money towards home health opportunities—keep patients home as long as possible.
 - More education needed for CNAs and CMAs.
 - Review the PCA program for better service/Increase the PCA reimbursement rate.

How could Minnesota’s organizations, service providers, and individuals influence more positive outcomes related to public awareness?

- Share more stories.

⁹⁰ These comments are verbatim from individuals who participated in the Conversation-in-a-Box experience.

- Change the narrative; people are still afraid to talk about it.
- Within the medical professions field you must (include) a certain amount of standardized continuing education credits.
- Required for medical students to have standardized practices and the same amount of education regardless of what specialty they are in. If you are a cancer specialist you should have some dementia training, etcetera.
- Be proactive – early intervention.
- Resource guides of local services.
- Financial information.
- Support groups.
- Respite care.
- Dementia-friendly day programs.
- Project Lifesaver.
- Volunteer programs – more community resources and outreach.
- Cultural sensitivity/awareness.
- Virtual Dementia Tour.
- Dementia Friends sessions.
- More employment leeway for caregivers.
- More education for the public.
- Doctors don't always diagnose the disease and name the type of dementia. There are tools that have been created for doctors to prepare them for delivering the news.

Diagnosis and treatment

Critical themes identified by the working group

- It would be nice to live well and (make) lifestyle changes a form of treatment.
- There's medication treatment and non-medication treatment such as staying active, living well, mental stimulation, and social engagement.
- How does the doctor/provider know what tools to use to diagnosis Alzheimer's disease? One participant mentioned two-hour assessment and MRI and he got his diagnosis and found that was beneficial. They talk about amyloids, Tau and plaques, and what that means.
- What research is being done in this area to help early diagnosis? One participant mentioned there's research being done for blood work to find these proteins and catch the disease early on instead of when it's in the middle/late stage.
- Living with the disease and what do you do after is important. Life habits and support is just as good as any medications out there. Learning to live with the disease and not (let it drive) you to depression.

How could Minnesota's state and local government influence more positive outcomes related to diagnosis and treatment?

- Group discussed that in SD care facilities a person without dementia is often paired with someone who has it as a roommate and they help each other. TRAINING - explored challenge of turnover and how to we determine proper trainers.
- Huge discrepancy with Medicaid/private pay/reimbursement. Often Medicaid isn't reimbursed as high as private pay making it difficult to pay employees thus leading to turnover.
- Often no consistency in reimbursement between counties/DHS/waivers.
- Fully cover caregiver support services.
- Require caregiver quality metrics in healthcare.
- Providers should be asking how their patient is affected by their caregiving experience/role, and provide support. This is an enormous blind spot that will have population health consequences. We need to pay attention.
- Work with national efforts to develop a much more robust and meaningful approach for issues related to caregiving in healthcare and society.
- Money to support community-based resources.
- Make training in aging and dementia awareness mandatory for all health care workers and providers including home care, nursing homes, hospitals, and clinics as well as any individual who comes in contact with this population.
- Support more locally-based caregiver support services. The costs of agency care is prohibitive for many, can we subsidize it (or utilize volunteers)?
- Make respite care affordable.
- Support more psychologists that specialize in Alzheimer's disease. Provide more ways to help people who are caring for those at home.

How could Minnesota's organizations, service providers and individuals influence more positive outcomes related to (topic category)?

- More research on cures.
- Support caregivers taking care of themselves.
- Research outcomes for those taken care of in the home vs. residential care.
- Again, training providers to be better prepared to deal with dementia and an aging population.
- Funding from our state Legislature.
- Continue to invite the community to events and encourage them to participate and get involved. Offer more panel discussions letting the community ask questions. It is important that we continue to do what we are doing with resources and education.
- Expand the "HABIT" program.

Residential services

Critical themes identified by the working group

- Facilities are reluctant to accept patients because of extreme requirements and scrutiny. They will have to stop neuroleptic and psychotropics that are prescribed during hospitalizations. Meanwhile CMS regulations want people out of hospital within 11-14 days.

- Lots of pressure on hospitals to move people out but facilities are very resistant to accepting them back because of behaviors/medications.
- Medicare guidelines for hospice services are too strict for Alzheimer's disease/dementia and often too close to end of life.
- There is difficulty placing people with "behaviors" often stereotyped as "trouble." There are no places that work with this specific population long-term, limited availability and willingness to accept, minimal commitment to keeping them despite challenges.
- This process of placement can be very traumatic for families, difficult decision, hard on everyone especially the caregiver who often feels as if they "failed."
- Staff needs is a huge issue, turnover, often fear of working with this population.

How could Minnesota's state and local government influence more positive outcomes related to residential services?

- Have different levels of funding (like a C.I.P rate for MR or developmentally delayed) to provide additional funding for therapeutic activities etc. as an incentive for facilities to be willing to accept more challenging patients, i.e., those with dementia.
- Re-evaluate regulations regarding neuroleptic usage in dementia in LTC settings and necessity of those medications long-term to treat behaviors associated with dementia. Allow justification for not being able to do dose reductions and increase awareness and understanding of for people creating the regulations re: the behaviors associated with dementia and the need for medications and the inability to decrease medications for those with heavy behaviors.

How could Minnesota's organizations, service providers and individuals influence more positive outcomes related to residential services?

- Increase understanding and education of dementia for the community and behavioral management education for LTC for dementia patients as well as their families and caregivers.
- Organizations need to acknowledge there is a problem.
- Put caregiver in the electronic health record – and use that information to help patients living with dementia and caregivers themselves.
- Healthcare and other organizations need to make sure families are given information and resources, especially when they receive a diagnosis – and at other teachable moments – they need to get information when they need it.
- We don't have brick and mortar solution to aging and specifically for dementia – we need innovative funding so that the families can help keep family members at home. We need to get creative about programs for home ownership, home accommodations (environment), and etcetera.
- All solutions should be culturally appropriate. Not all people respond to the same things. We have to be sensitive to diversity and views on how support is received.

Bonus feedback – caregivers

One conversation group chose not to discuss any of the topics listed. Instead, they chose to focus on caregivers. They offered this explanation: “It is clear that issues pertaining to caregivers are not covered directly within any of the sub-committees of Alzheimer’s Disease Working Group, but it is a persistent theme in all of our community conversations, and we believe caregivers and caregiving should be a major focus for Alzheimer’s Disease Working Group and state efforts.”

Critical themes that emerged from conversations

- Dementia/Alzheimer’s seems to be where the recovery/addiction field was in the 1970s, and we could learn a lot from that experience; there are many similarities/parallels. We need language and legal methods to include them more meaningfully. Dementia/Alzheimer’s disease is a family disease! It affects the entire family, not just one person. We need to treat the entire family. There are many examples of families being generally ignored when it comes to dealing with this disease/condition – and families and society suffers because of it. People are silently suffering alone, and no one is paying attention. Family is the biggest part of the solution!
- Caregivers are not identified even in their own doctor’s visits. There are many experiences where a patient, who self-identifies as a caregiver for someone living with dementia, mentions this to their own doctor and the doctor never asks more about it or pays any attention to it. Doctors don’t seem to have any interest whether someone is negatively affected by their caregiver role at home. Caregiver burden becomes ever greater the longer the disease progresses. There is so much more our healthcare system can do here.
- When it comes to dementia, we tend to focus on our own limited scope of literature. There is a lot of overlap between issues of dementia and aging in general, as well as retirement (forced retirement). We need to expand the breadth of literature we are looking at so that we can be more holistic as a society. Dementia and AD crosses many areas beyond healthcare – it brings up many social and other issues that need to be examined.

How could Minnesota’s organizations, service providers, and individuals influence more positive outcomes related to (topic category)?

- In the medical field, we need to identify caregivers in the electronic health record. It could be included as a vital sign. It should be updated often. Caregivers should not only be named, but also included in care, decisions, and conversations. Our health system is not set up to treat patients holistically, which is a barrier. Doctors focus on treating the patient; that is who they can legally work with and who they can bill for. This sets up a barrier; doctors don’t turn to caregivers as a result.
- The medical system uses HIPAA to block families from participating or being included – and this needs to change. HIPAA actually originated out of recovery/addiction field due to stigma – it should protect people, but not block them from getting the help they need, which means including family. (NOTE: family is loosely defined here....we’re not just talking about blood relatives).

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