



North Dakota Alzheimer's and Dementia State Plan

Current Status of, and Recommendations for, Meeting the Needs of Individuals and Families with Alzheimer's Disease and Other Dementias

March 2022

PREPARED BY:

RESEARCH AND WRITING TEAM

Shawnda Schroeder, PhD, MA

Department of Indigenous Health,
University of North Dakota
School of Medicine & Health Sciences

Rebecca Quinn, MSW, LMSW

Center for Rural Health,
University of North Dakota
School of Medicine & Health Sciences

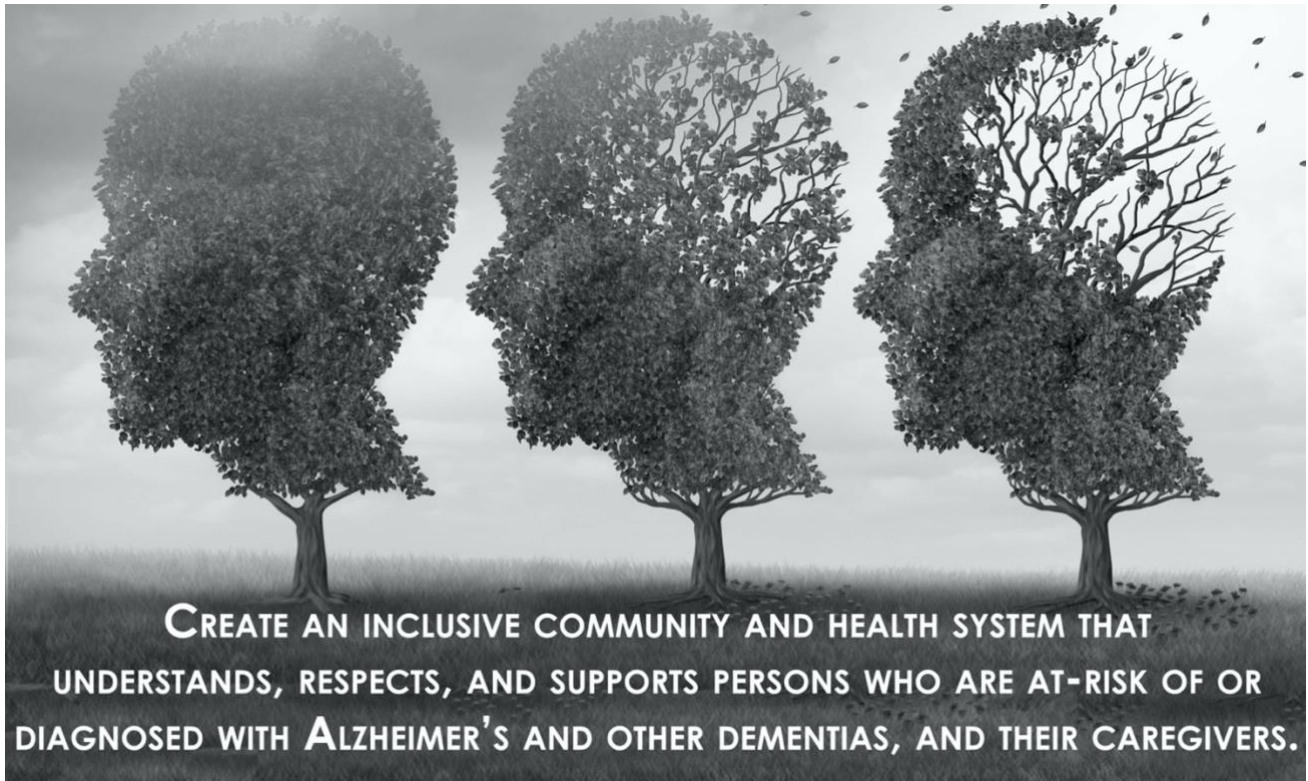
Laura Hand, PhD, MPP

Political Science and Public Administration
and Masters of Public Health,
University of North Dakota

Gretchen Dobervich, LBSW

Public Health Policy Manager
North Dakota State University

VISION STATEMENT



ACKNOWLEDGEMENTS

Many people made significant contributions to the creation of this state plan. We want to thank our contributors listed on page 3 for helping to create the overall vision and direction of the plan, reviewing research design, providing additional resources and information, and giving detailed feedback on multiple drafts of this document. They also graciously provided their expertise during key informant interviews. We would also like to thank our focus group participants who generously offered their time, expertise, and experience, providing invaluable information that directly informed the findings and recommendations. The focus group participants also helped the research team understand the complexity of dealing with Alzheimer's and other dementias, and the dedication, care, tenacity, and humanity of North Dakotans, coping with the disease. Two University of North Dakota (UND) graduate students, Amber Buzick and Matthew Campion, contributed research and assisted with interviews and focus groups as temporary, but very active, members of the research team. Finally, we would like to thank the staff at the Center for Rural Health (CRH) for assisting with report design.

Table of Contents

DEFINITIONS	6
EXECUTIVE SUMMARY	7
Three Themes of Need in North Dakota	7
Five Actionable Goals for North Dakota	8
DEVELOPING THE STATE PLAN: THE PROCESS	9
Creating Working Groups	9
Identifying the Need: Review of the Data	11
DIVERSITY, INCLUSION, AND CULTURAL CONSIDERATIONS	12
American Indian/Alaskan Native	13
African American	15
Hispanic	15
Asian/Pacific Islander	16
Broad-based Diversity, Inclusion, and Cultural Considerations	16
PREVIOUS STATE PLAN FOR ALZHEIMER’S AND DEMENTIA	17
Impact of the 2007 State Plan	18
DEFINING ALZHEIMER’S DISEASE AND DEMENTIA	20
Prevention, Diagnosis, and Treatment	21
A DATA SNAPSHOT	23
Data from the 2019 Behavioral Risk Factor Surveillance System ³⁶	25
OPPORTUNITIES TO ADDRESS THE IMPACT OF ALZHEIMER’S DISEASE AND DEMENTIA ON THE HEALTH OF NORTH DAKOTA	25
Three Themes of Need in North Dakota	26
SUMMARY OF NEED	32
RECOMMENDATIONS FOR NORTH DAKOTA	34
Five Actionable Goals for North Dakota	34
CONCLUSION	43
CITATIONS	44
Appendix A: North Dakota Department of Health Organizational Chart	46
Appendix B: List of Internal Development Team, Advisory Group Members, and Stakeholders	47
Appendix C: Data Sources	49
Appendix D: Focus Group Questions	51
Appendix E: Key Informant Interview Protocol	53
Appendix F: 2007 State Plan for Alzheimer’s Disease	55

List of Tables

Table 1. Perceived Barriers to Getting Excellent Healthcare and Support for Alzheimer’s or Another Dementia Among U.S. Adults	12
Table 2. Types of Discrimination Based on Race, Color, or Ethnicity Among Alzheimer’s and Dementia Caregivers	12
Table 3. Percent of Those Ages 45+ with Subjective Cognitive Decline in North Dakota	24
Table 4. Healthy People 2030 Goals and Objectives that Relate to Alzheimer’s and Other Dementias ⁶	33

List of Figures

Figure 1. States with State Alzheimer’s Disease Plans by Year Created/Updated	16
Figure 2. Projected Number of People Age 65 and Older in the U.S. Population with Alzheimer’s Dementia, 2020-2060	19
Figure 3. Annual Mortality Rate/100,000 people due to Alzheimer’s Disease by State, 2019	22
Figure 4. Percent of North Dakota with Memory Problems who say it Creates Difficulties and Burden, 2019	24
Figure 5. Proportion of Caregivers of People with Alzheimer’s or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015	29
Figure 6. Work-related Changes Among Caregivers of People with Alzheimer’s or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving	30
Figure 7. Alzheimer’s Disease (AD) Continuum	35

ACRONYMS

CPT	Current Procedural Terminology
CRH	Center for Rural Health
MCI	Mild cognitive impairment
NDDHS	North Dakota Department of Human Services
NDDoH	North Dakota Department of Health
NDSU	North Dakota State University
PCP	Primary Care Physician
UND	University of North Dakota
U.S.	United States
CDC	Centers for Disease Control and Prevention
ADA	American Disabilities Act
COPD	Chronic obstructive pulmonary disease
LGBTQ2S+	Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, and Two-Spirit

DEFINITIONS

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 walk, eat, drink, and communicate. ¹
Caregiver	Person providing care to someone with Alzheimer’s disease or other dementias. Caregivers can be family members, friends, or professional caregivers. Caregivers may provide full- or part-time help to the individual with dementia and may or may not be paid. ²
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. ¹
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. ³ Dementia-capable healthcare systems are “those that provide individualized, coordinated, and integrated medical and psychological care for patients and their care partners, delivered by cohesive teams of clinicians, staff, and healthcare administrators.” ⁴
Dementia friendly	“A town, city, or country that is informed, safe and respectful of individuals with the disease, their families and caregivers and provides supportive options that foster quality of life.” ⁵
Mild cognitive impairment	“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.” ¹
Medicaid	A joint federal and state program that helps with medical costs for qualified individuals with limited income and resources. Medicaid can also provide benefits not normally covered by Medicare, including long-term nursing home care and personal care services. ²
Medicare	Medicare is a federally-funded government health insurance program for people aged 65 and older and for certain younger individuals with disabilities. ²
Palliative care	Palliative care includes medical and/or surgical methods to ease the pain of a serious or incurable illness. ²
Person-centered care	Healthcare and social services designed to reflect the individual’s unique preferences, values and needs, identified and agreed upon in partnership with the medical providers, the patient, and other family members when appropriate. The goal is for people to be treated as individuals and to receive appropriate and timely care that meets their needs. ²
Respite care	Provides a caregiver temporary relief from the responsibility and stress of caring for individuals with chronic physical or mental disabilities. Examples of respite care include in-home assistance, a short or long-term care facility stay, or day care programs for adults. ²
Subjective Cognitive Decline	The self-reported experience of worsening or more frequent confusion or memory loss.

EXECUTIVE SUMMARY

North Dakota reports the fourth highest mortality rate for Alzheimer's disease in the United States (U.S.) at 52.9 per 100,000 North Dakota residents. The rate for the U.S. is 37 per 100,000 residents. Although leading in mortality, North Dakota is one of a few states with a State Plan for Alzheimer's and Dementia over 12 years old. This plan was written in July of 2007 and is less than two pages. Although it does mention Alzheimer's and other other dementias, it does not specifically outline a plan to address services for those living with, or supporting those living with, dementia in North Dakota.

This current state plan, developed in 2021, reviewed existing data, involved stakeholders and community members, and identified strengths in the current plan as well as opportunities to reach the following vision: *Create an inclusive community and health system that understands, respects, and supports persons who are at-risk of or diagnosed with Alzheimer's and other dementias, and their caregivers.*

Three Themes of Need in North Dakota

North Dakota must address, in no particular order, the following community needs in order to achieve the set vision of an inclusive community and health system:

1. **Early Detection and Diagnosis**

There is a need to create a strong system of early detection and diagnosis through public education campaigns (early warning signs) and training of providers in all healthcare settings.

2. **Education and Awareness**

There is a need to provide education and awareness campaigns that target the public, persons at-risk of Alzheimer's and other other dementias, providers, and caregivers.

3. **Supports for Caregivers**

Caregivers need comprehensive support throughout the life course of the disease. The state must identify or develop comprehensive community programs that are well advertised, affordable, and integrate social supports for caregivers. Supports exist but can be difficult to navigate, unaffordable, or unavailable.



Five Actionable Goals for North Dakota

Healthy People 2030 has a specific goal to “Improve health and quality of life for people with dementia, including Alzheimer’s disease.”⁶ This goal is measured through three specific objectives. Healthy People 2030 goals focus on three objectives:

- Increase the proportion of older adults with dementia, or their caregivers, who know they have it.
- Reduce the proportion of preventable hospitalizations in older adults with dementia.
- Increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider.

This state plan has identified five actionable goals, that if addressed, would also assist in North Dakota moving the needle to reach the Healthy People 2030 goals around Alzheimer’s and other dementias and would promote the shared vision of creating an inclusive community and health system that understands, respects, and supports persons who are at-risk of or diagnosed with Alzheimer’s and other dementias and their caregivers.

1. Comprehensive Care Over the Full Continuum of the Disease
2. Support for Research
3. Caregiver and Community Education and Supports
4. Workforce Development, Education, and Collaboration
5. Identify and Address Diversity in Research, Supports, and Care Access

DEVELOPING THE STATE PLAN: THE PROCESS

The state plan for Alzheimer's and other dementias was funded in October 2020 to identify need, convene work groups, and propose action items and goals for the state within a twelve-month timeframe. Given this project took place during the global health pandemic (COVID-19), meetings, interviews, and focus groups had to occur by phone and video conferencing.

Creating Working Groups

The contracted team of four from University of North Dakota (UND) and North Dakota State University (NDSU) met with the North Dakota Department of Health (NDDoH) immediately upon funding to begin to identify partners and determine their role in the development of the state plan. Stakeholder and colleagues were identified as a member of one of three groups:

- Internal state plan development team
- Advisory group
- Stakeholder group

Internal State Plan Development Team

The internal development team included the four authors of the report, representatives Melissa Kainz and Janna Pastir from the NDDoH Division of Health Promotion, and representatives Beth McMullen and Josh Ney from the Alzheimer's Association Minnesota-North Dakota Chapter. This team met regularly to identify potential data sources, discuss the vision of the state plan, and offer the names of potential advisory group members and stakeholders. This group was responsible for the development of the plan, review of all content, and final release of this report.

Advisory Group

The role of the advisory group was to inform the internal development team and to review the data, making recommendations for further data review or additional analyses. This team met regularly and also provided insight on the vision statement, questions to ask of focus groups and key informants, analysis of the qualitative data, and recommendations for the state, based on the data. This group also provided critical review of the final state plan before release.

Stakeholders: Focus Groups and Key Informant Interviews

The internal development team all contributed names of colleagues, stakeholders, and community members who would serve well on focus groups or who could serve as key informants. It was imperative that these individuals had diverse perspectives and a level of knowledge around care and support for persons with dementia. These individuals included caregivers, providers, social workers, tribal health representatives, educators, persons with lived

experience, insurers, and more. See Appendix B for a complete list of all stakeholders, advisory group members, and the internal development team.

Identifying the Need: Review of the Data

Partners within the NDDoH and the Department of Human Services (NDDHS) as well as colleagues serving on the advisory group, provided a list of potential data sources to review in order to conceptualize the current status of Alzheimer's and other dementias in North Dakota. When possible, data were reviewed by sociodemographic variables and compared to other states or national benchmarks. In review of the data, the advisory group and internal development team also took note of data limitations and recommendations for the state. See Appendix C for a complete list of the data sources reviewed in the development of the state plan.

Qualitative Research: Identifying the Need

To capture the expertise and personal experiences with providing services to or caring for a person with Alzheimer's and other dementias in North Dakota, the research team engaged in key informant interviews and focus groups. Protocols for the interviews and focus groups were reviewed and approved by the Institutional Research Boards at both UND and NDSU before the interviews took place. Interviews and focus groups were conducted via Zoom and video recorded with participant permission to ensure accuracy during the analysis stage. See Appendix B for the list of organizations or groups that were represented by focus groups and key informant interviewees. See Appendix D for the focus group questions. See Appendix E for the key informant interview protocol.

Key informant interviews were completed with the members of the advisory group. The interviews had three primary purposes: to gather information from identified experts about the state of Alzheimer's care in North Dakota, to use this information to design the focus group questions, and to begin to build recommendations for future action.

Focus group recruiting was conducted via email. Members of the advisory group and research team circulated an invitation to participate through personal and professional channels. Potential focus group participants responded with their availability and role in Alzheimer's care, so the research team could create focus groups that contained diverse perspectives. The research team held five focus groups over two weeks, each lasting about two hours. Focus group size ranged from two to seven participants.

Qualitative Research: Identifying Recommendations

Identifying and outlining the recommendations was an iterative and collaborative process that combined the results from the interviews and focus groups with current research and literature. The research team met and created an initial set of recommendations, which were then presented to the advisory group. The advisory group discussed each recommendation, including queries into how and why the recommendation was created. Information from that discussion resulted in reconfiguring and refining the final recommendations.

DIVERSITY, INCLUSION, AND CULTURAL CONSIDERATIONS

Alzheimer's disease is ranked in the top 10 causes of death for men and women in the U.S. across races.⁷ While Alzheimer's disease knows no gender, racial, or geographic boundaries, there are cultural considerations, which impact diagnosis, treatment, and care of persons with Alzheimer's disease.

Accounts of dementia date back as far as 2000 B.C. in Egyptian history. Historically, some Asian cultures have viewed dementia as the "philosophical death" of an individual, and in some parts of Africa, persons with dementia have been punished as witches as recently as 2010. Over the course of time, Anglo cultures have regarded dementia as punishment for sins, witchcraft, and as a mental illness due to character defect rather than a neurological disease.⁸ The long history of stigma associated with Alzheimer's disease and dementia is a modern-day barrier in seeking a diagnosis and treatment across cultures and ethnicity.

The biological markers of Alzheimer's disease, beta amyloid plaque and tau protein tangles in the brain, were discovered in 1906 by Dr. Alois Alzheimer. This discovery occurred through the brain autopsy of a patient in her 50s under his care at a mental institution.⁸ Brain autopsy is used in many Alzheimer's disease and other dementia research. While there is no single biologic test for Alzheimer's disease, brain autopsy can confirm a diagnosis postmortem.

Respect for culture, religion, and tradition should be exercised, when providing information about brain autopsy or inviting persons with Alzheimer's disease, their caregivers, and family members to participate in research that would require a postmortem brain autopsy. The Islamic faith forbids autopsy, as it is believed a person continues to feel pain after death and burial of the deceased occurs within 24 hours of death.⁹ The burial ceremonies for many American Indian cultures do not allow for autopsy, as it is viewed as desecrating a person's body and will interfere with their death journey.

Limited data exists on Alzheimer's disease and other dementias and caregiving for American Indians and Alaskan Natives, refugees, and New Americans. Overall, there is an underrepresentation of non-White participants in Alzheimer's disease research.⁸ Researchers, working in collaboration with non-White communities of color and marginalized communities, presents opportunity to learn more, aimed at developing best practices for care, education, and support.

Tables 1-2 illustrate the variability by race surrounding barriers to care and experiences of discrimination in care among Alzheimer's and dementia caregivers.¹⁰ These tables are provided by the Alzheimer's Association.

Table 1. Perceived Barriers to Getting Excellent Healthcare and Support for Alzheimer’s or Another Dementia Among U.S. Adults ¹⁰

Perceived Barriers to Getting Excellent Health Care and Support for Alzheimer’s or Another Dementia Among U.S. Adults

	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Affordability of care	61%	55%	52%	70%	61%
Lack of good health care insurance coverage	31%	41%	31%	39%	36%
Lack of good health care services in my community	20%	24%	27%	27%	24%
Lack of family and social support to help me	20%	21%	20%	25%	20%
Being treated differently because of my race, color, or ethnicity	1%	18%	36%	19%	12%
Not being able to communicate easily in English	4%	9%	9%	8%	5%
Other barriers	2%	1%	1%	1%	2%
There would be no barriers	21%	17%	20%	12%	14%

Table 2. Types of Discrimination Based on Race, Color, or Ethnicity Among Alzheimer’s and Dementia Caregivers ¹⁰

Types of Discrimination Based on Race, Color or Ethnicity Among Alzheimer’s and Dementia Caregivers

	White Americans	Hispanic Americans	Black Americans	Asian Americans	Native Americans
Felt not listened to	17%	28%	42%	30%	31%
Provider acted like you were not smart	11%	26%	28%	28%	43%
Treated with less courtesy than others	11%	26%	26%	23%	22%
Treated with less respect than others	8%	24%	26%	20%	27%
Received poorer service than others	7%	21%	19%	10%	18%
Provider acted afraid of you	7%	11%	13%	7%	4%

American Indian/Alaskan Native

As life longevity expectancy increases for American Indians and Alaskan Natives, so does the risk for developing Alzheimer’s disease. According to the Centers for Disease Control and Prevention (CDC), the number of American Indians and Alaskan Natives, age 65 and older living with memory loss, will increase five times between 2014-2060.⁸ In response to the growing number of American Indians and Alaskan Natives experiencing memory impairment, the CDC and Alzheimer’s Association developed the tribally informed [Healthy Brain Initiative Road Map for Indian Country](#).¹¹

Eight public health strategies were identified for integration and implementation into tribal primary and public health programs and services for Elders and the broader community.

These eight strategies are: ¹¹

Educate and Empower Community Members

1. Work with community members to understand brain health, early warning signs of dementia, and benefits of early detection and diagnosis for persons with dementia and their caregivers.
2. Encourage community members to use effective interventions, best practices, and traditional wellness practices to protect brain health, address cognitive impairment, and support persons with dementia and their caregivers.
3. Provide information and tools to help older adults with dementia and their caregivers anticipate and respond to challenges that typically arise during the course of dementia.
4. Promote engagement among tribal leaders in dementia issues by offering information and education on the basics of cognitive health and impairment, the impact of dementia on caregivers and communities, and the role of public health approaches in addressing this priority problem.

Collect and Use Data

5. Support collection and use of local data on dementia and caregiving in Indigenous communities to plan programs and approaches.
6. Promote the inclusion of healthcare quality measures that address both cognitive assessments and the delivery of care to Indigenous communities with dementia.

Strengthen the Workforce

7. Educate healthcare and aging services professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia.
8. Educate healthcare and aging services professionals on the best ways to support families and caregivers of older adults with dementia.

The Alzheimer's Association Minnesota-North Dakota is also a source of American Indian Alzheimer's disease and other dementias information. The Alzheimer's Association Minnesota-North Dakota Chapter is adapting professional, community, and caregiver education to be culturally responsive. Professional and family caregiver care consultation services are available to American Indians, living in urban and tribal communities across North Dakota.

African American

African Americans age 65+ have an Alzheimer's disease incidence rate of 18.6%, compared to 10% of White Americans age 65+.⁷ This disparity in Alzheimer's disease incidence is attributed to greater incidences of chronic diseases, which increased risk of dementia, such as heart disease, hypertension, and diabetes, related to inequities in social determinants of health, including but not limited to access to healthcare, nutrition access, and structural racism.⁷

The terms used in treating and caring for African American persons with Alzheimer's disease and other dementias, their caregivers and family can impact the utilization of care and services. Using the terms "memory loss" and "fellowship" versus "dementia" and "support groups" were found to be more effective in engaging African Americans in attending Alzheimer's disease community education and caregiver support services.¹² Providing care for an ill family member is perceived as a responsibility rather than a burden in African American families. Care should be taken when referring to "the burden of caregiving."

African American communities have strong spiritual and social ties to faith communities. Working in collaboration with churches opens opportunities to reach the community with information, regarding Alzheimer's disease and other dementia warning signs, diagnosis, treatment, and care. The Alzheimer's Association has developed culturally responsive informational materials for African Americans, including a toolkit entitled Serving African American Families.¹² Professional and family caregiver care consultation services are available to African Americans, living in urban and tribal communities across North Dakota.

Hispanic

Hispanic Americans age 65+ have an Alzheimer's disease incidence rate of 14%, compared to 10% of White Americans age 65+.⁷ As with Black Americans, Hispanic American's increased incidence of Alzheimer's disease is attributed to chronic diseases, which increased risk of dementia and inequities in social determinants of health.⁷ Caring for ill family members is the responsibility of women in Hispanic culture; typically a female relative will emerge as the primary caregiver.¹³ Hispanic homes are often multigenerational with strong intergenerational relationships and support.¹⁴ Advice and referrals from family drive persons to seek care outside the family, such as seeing a medical provider.¹⁴

Hispanic culture is heavily influenced by the Roman Catholic Church. Working in collaboration with churches opens opportunities to reach the community with information, regarding warning signs, diagnosis, treatment, and care. The Alzheimer's Association has many informational resources, translated into Spanish, and Spanish language services are available through their 24/7 helpline. Professional and family caregiver care consultation services are available to Hispanic people, living in urban and tribal communities across North Dakota.

Asian/Pacific Islander

Asian culture values saving face and bringing honor to one's family. Alzheimer's disease and other dementias have been viewed as dishonorable or shameful and reduce the likelihood for seeking diagnosis and treatment as well as care and caregiver supports. Emphasis is placed on family caregiving in Asian families, and the stigmatization of Alzheimer's disease and other dementias can result in lack of caregiver supports and services.¹⁵ In many Asian cultures, memory loss is viewed as a normal part of the aging process. This cultural belief may lead many people with cognitive impairment to not seek medical care.¹⁵ This reluctance to seek care can result in non-dementia medical issues going untreated, and if the person does have Alzheimer's disease or other dementia, in delayed diagnosis and treatment.

The Alzheimer's Association and the National Asian Pacific Center on Aging developed a toolkit entitled [Strengthening Community-Based Services for Asian American and Pacific Islanders Affected by Dementia](#).¹⁶ This toolkit identifies best practices for diagnosis, treatment and care:

1. Make diversity training and education a priority.
2. Create culturally and linguistically appropriate diagnostic and educational materials and services.
3. Widely distribute information throughout the community with emphasis placed on ethnic media and cultural events.
4. Help more families access local dementia-capable, long-term services and supports through ethnic and culturally-based programs and services collaborations.

Broad-based Diversity, Inclusion, and Cultural Considerations

This North Dakota Alzheimer's and Dementia State Plan lacks inclusion of diverse perspectives, experiences, and data. While intentional efforts were made to include more diversity in the development of this plan, focus groups and key informant interviews were conducted virtually due to the COVID-19 pandemic. It is recommended that the work of developing this plan be continued, and focus groups and key informant interviews of medical providers, persons with Alzheimer's disease, their caregivers, and families be conducted utilizing culturally responsive approaches, such as in-person discussions within racially and geographically diverse communities in North Dakota.

While increased need for early diagnosis and treatment was a concern across North Dakota, a deeper knowledge of the diagnosis and treatment process and experience, based on racial and cultural diversity, is recommended. This knowledge is key to developing interventions and supports for North Dakotans least likely to seek out or be offered care.

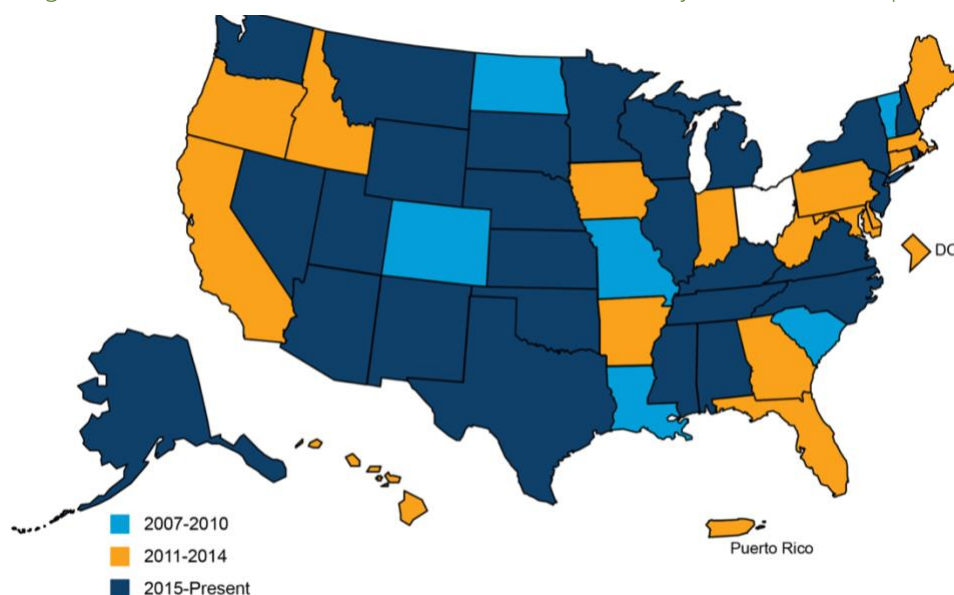
PREVIOUS STATE PLAN FOR ALZHEIMER’S AND DEMENTIA

The [State Plan for Alzheimer’s and Dementia](#)¹⁷ was written in July of 2007. See Appendix F. On September 14, 2018, Governor Doug Burgum signed the [North Dakota State Plan on Aging](#)¹⁸ under the Older Americans Act. Although it does mention Alzheimer’s and other other dementias, it does not specifically outline a plan to address services for those living with, or supporting those living with, dementia in North Dakota. Specifically, the North Dakota State Plan on Aging provides:

direction for continued development of a comprehensive and coordinated system of home and community-based services that enable older individuals and adults with physical disabilities to remain safe, active, and healthy in their own homes and communities. The plan serves as a planning and compliance document that allows the State to receive federal funds for service provision. This plan was developed by the Department of Human Services, Aging Services Division, in accordance with the Older Americans Act of 1965, as amended (Public Law 114-144). [North Dakota State Plan on Aging, page i]

According to the Alzheimer’s Association, since 2007, 49 states, the District of Columbia, and Puerto Rico have published state plans to address Alzheimer’s disease. The Alzheimer’s Association also recommends that states review and revise their plans every three to five years to ensure they accurately reflect current state needs and best practices.¹⁹ North Dakota has not updated their plan in 13 years. See Figure 1.

Figure 1. States with State Alzheimer’s Disease Plans by Year Created/Updated¹⁹



Impact of the 2007 State Plan

In 2004, the NDDoH received a federal Alzheimer's disease demonstration grant to increase availability of services for diagnosis and support services. While support services through the federally-funded Family Caregiver Support Program and the state-funded North Dakota Dementia Care Services Program have increased access, obtaining a diagnosis remains a concern. In 2007, the North Dakota Legislature passed House Concurrent Resolution 3022 to conduct a study of availability and future needs for dementia-related services and program funding.²⁰ The study report has served as the State's Alzheimer's Disease State Plan.¹⁷

Senate Bill 2070 was passed in 2007. This legislation appropriated funds and directed the NDDHS to establish the Aging and Disability Resource Center. The Center would provide a single point of entry to care for elderly and/or disabled North Dakotans. The department maintains the [Aging & Disability Resource Link](#)²¹ website, which offers a toll-free telephone line answered Monday-Friday 8:00 am-4:30 pm and an option to complete an information request form and submit it online. The website does have a link to the Alzheimer's Associations website and the number for the Alzheimer's Associations 24/7 helpline.

One of the most significant Alzheimer's disease and other dementia impacts in North Dakota has been funding for NDDHS to contract out the development and management of the North Dakota Dementia Care Services Program. This program aims to improve disease management and increase caregiver support through care consultation, physician outreach, and community and professional education. Between January 2010 and September 2020, the program has supported 3,328 families of persons with Alzheimer's disease or another dementia, provided 11,896 care consultations to 6,898 caregivers, and provided education to 44,018 people across North Dakota in 52 counties.²²

An evaluation of the North Dakota Dementia Care Services Program showed the state's investment of \$2.2 million, resulted in an estimated savings of \$39.2 million in reduced hospitalizations, emergency room visits, and delaying skilled, long-term care placement.²²

Increasing the appropriation to the North Dakota Dementia Care Services Program would provide increased access to the community-based supports of care consultation and education, continue, expand collaborations to increase diagnosis and treatment, and provide cost savings for families and the State.

NDDHS received a federal Real Choice Systems Change grant in 2004. This grant provided funds to states to develop options and access to a continuum of long-term care services. The development of community-based care options continues with the 2020 Olmstead Ruling.²³

Olmstead Ruling

The Americans with Disabilities Act (ADA), signed into federal law in 1990, prohibits discrimination against persons with disabilities and guarantees them the same opportunities as non-disabled persons. In 1999, the United States Supreme court ruled in *Olmstead v. L.C.*²³ that the segregation of persons with disabilities was discrimination and a violation of the ADA. The ruling requires states to provide community-based services for persons with disabilities, when appropriate.²³

The Civil Rights Division of the United States Department of Justice began enforcing *Olmstead v. L.C.* in 2009.²³ A 2015 investigation into North Dakota's implementation of the Olmstead ruling found "North Dakota discriminates against individuals with physical disabilities by unnecessarily institutionalizing them in nursing facilities, instead of providing them the services they need to live in the community."²³ North Dakota and the Department of Justice reached an agreement in December of 2020 to resolve complaints of *Olmstead v. L.C.* violations.²³

Under the agreement, the state of North Dakota has eight years (2028) to implement individualized assessments for persons with disabilities currently living in nursing facilities to determine supports and services necessary to live in the least restrictive setting, move individuals, who wish, with disabilities living in nursing facilities to community-based housing with support services, and expand community-based care services for adults with physical disabilities.²³

The North Dakota Olmstead Ruling has great potential to extend the time a person with Alzheimer's disease is able to live at home through the expected expansion of home modification services, nurse home visiting programs, medical transportation, and home care personal care services.

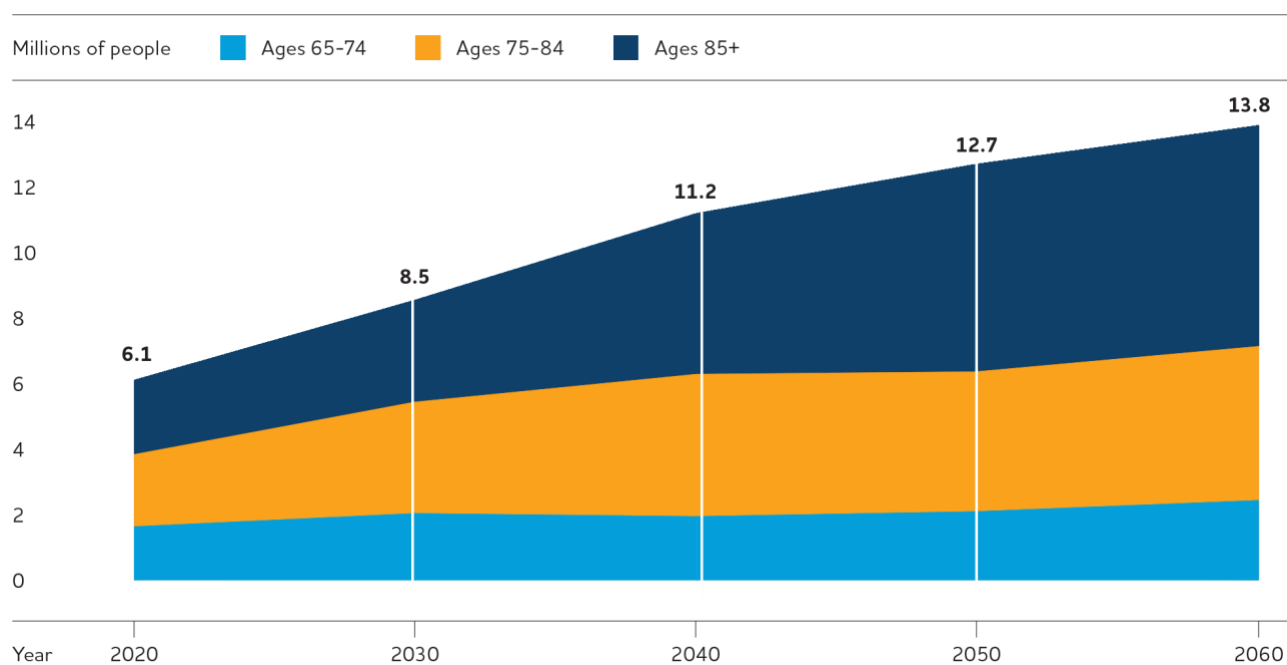
DEFINING ALZHEIMER'S DISEASE AND DEMENTIA

Alzheimer's disease is a mind-altering brain disorder, impacting memory, cognition, and behaviors. It is fatal. Alzheimer's is a progressive, irreversible disease and is the most common cause of dementia. Dementia is a general term for memory loss and/or loss of other cognitive abilities that are serious enough to interfere with activities of daily living.²⁴

Alzheimer's disease accounts for between 60-80% of all dementia cases in the U.S. Although mild memory loss may be a normal part of aging, Alzheimer's and other dementias are not!

More than 6 million Americans age 65 and older are living with Alzheimer's.¹⁰

Figure 2. Projected Number of People Age 65 and Older in the U.S. Population with Alzheimer's Dementia, 2020-2060¹⁰



Prevention, Diagnosis, and Treatment

There is likely no single cause to Alzheimer's disease, but rather, several risk factors that can increase the odds of being diagnosed with Alzheimer's or other other dementias. There is no cure for Alzheimer's, but there are treatments that may change disease progression and drug and non-drug options that may help treat symptoms. However, [these treatment options remain limited](#), and there is a body of research, focused on the scientific evidence, around reducing risk through individual behavior and other mitigating factors.²⁵

Risk Factors for Alzheimer's Disease and Other Dementias

Some of the risk factors for Alzheimer's and other dementias cannot be changed. These factors include age, family history, and heredity. However, more emerging evidence around healthy behaviors, which have been shown to prevent cancer, diabetes, and heart disease, may also reduce risk for subjective cognitive decline.²⁶ These include protecting the brain from injury, heart health, and overall healthy aging through eating a healthy diet, remaining socially and physically active, and avoiding use of tobacco and excess alcohol.

Ten Warning Signs of Alzheimer's

Alzheimer's and other dementias cause memory, thinking, and behavior changes that interfere with daily living. Common warning signs include:²⁷⁻²⁸

- 1 Memory loss that disrupts daily life**
- 2 Challenges in planning or solving problems**
- 3 Difficulty completing familiar tasks**
- 4 Confusion with time or place**
- 5 Trouble understanding visual images and spatial relationships**
- 6 New problems with words in speaking or writing**
- 7 Misplacing things and losing the ability to retrace steps**
- 8 Decreased or poor judgement**
- 9 Withdrawal from work or social activities**
- 10 Changes in mood and personality**

Access the [10 Warning Signs of Alzheimer's Worksheet](#)²⁸ from the Alzheimer's Association for more details around signs of dementia, compared to typical age-related changes in memory.

Diagnosing Alzheimer's

Early and accurate diagnosis is crucial to slowing the progression of Alzheimer's. While there is no single test to determine if someone has dementia, doctors may take multiple steps to determine the cause of memory and thinking problems, such as a careful review of medical history, physical examination, laboratory tests, and the characteristic changes in thinking, day-to-day function, and behavior associated with each type. While physicians can almost always determine if a person has dementia, it may be difficult to determine the exact cause in some cases. Individuals responsible for conducting assessments include primary care providers, a doctor trained in brain conditions (neurologist), or a doctor trained to treat older adults (geriatrician). The examination of brain tissue upon autopsy can confirm the cause and also contribute to research about Alzheimer's disease and other dementias, including research into new treatments.²⁹⁻³⁰

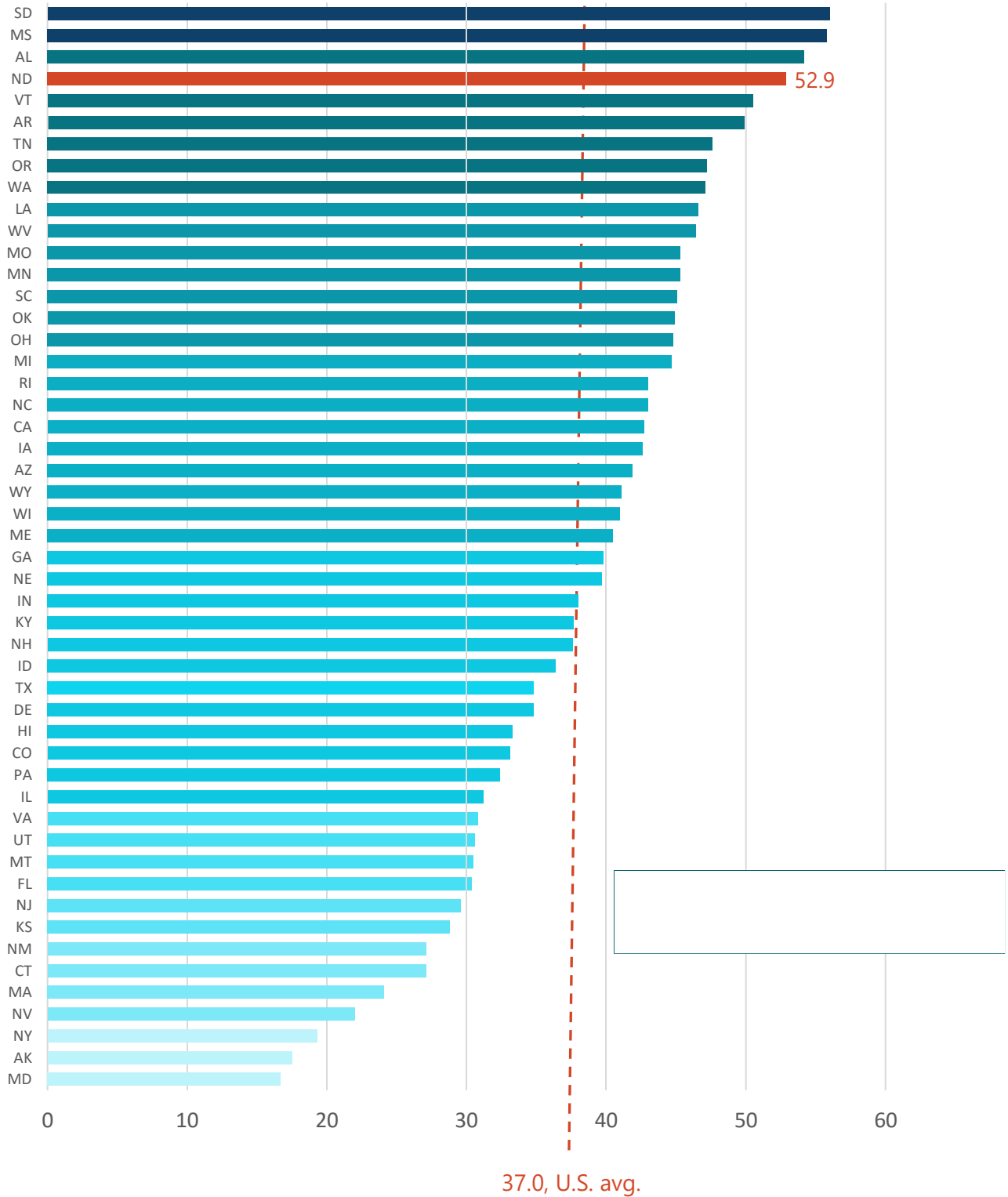
Learn More about Prevention, Diagnosis, and Treatment

Reputable and national resources around the prevention, diagnosis, and treatment of Alzheimer's are available through:

- The [Alzheimer's Association](#)³¹
- The [National Institute on Aging](#)³²
- The [Centers for Disease Control and Prevention](#)³³
- The [North Dakota Department of Health](#)³⁴

A DATA SNAPSHOT

Figure 3. Annual Mortality Rate/100,000 People due to Alzheimer’s Disease by State, 2019 ¹⁰



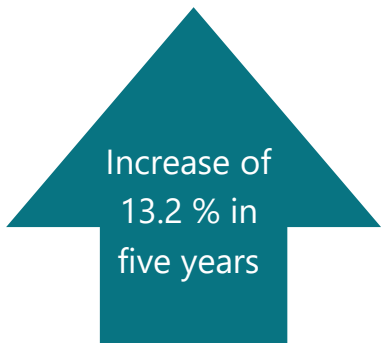
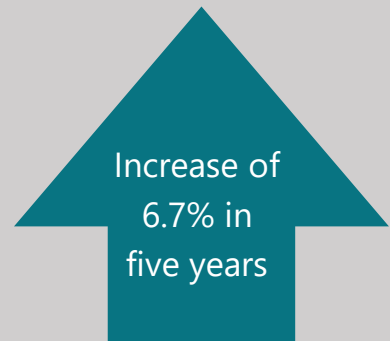
As of 2018, there were 19 board certified geriatricians in North Dakota. According to the American Geriatrics Society's Geriatrics Workforce Policy Center, "it's projected that approximately 30% of the 65-plus patient population will need to be cared for by a geriatrician and that each geriatrician can care for a patient panel of 700 older adults. Based on these numbers, approximately" **65 geriatricians will be needed by 2030** to care for the roughly 45,707 most vulnerable adults, ages 65 and older in North Dakota.³⁵



15,000 North Dakotans age 65 and older with Alzheimer's dementia in North Dakota as of 2020.¹⁰



16,000 North Dakotans age 65 and older are projected to have Alzheimer's dementia in North Dakota as of 2025.¹⁰



In 2020, the total Medicaid payments for North Dakotans age 65 and older living with Alzheimer's or other dementias was **\$190 million**.¹⁰

The projection for 2025 in North Dakota is **\$215 million in total Medicaid** payments for North Dakotans age 65 and older living with Alzheimer's or other dementias.¹⁰



In 2020, **19,000 persons** provided roughly **29 million hours of unpaid care** for people in North Dakota with Alzheimer's and other dementias at a value of **\$521 million**.¹⁰

Data from the 2019 Behavioral Risk Factor Surveillance System ³⁶

In North Dakota, 8.1% of those aged 45 and over report they are experiencing confusion or memory loss that is happening more often or is getting worse. This loss is understood as subjective cognitive decline.



Nearly two-thirds, (64.8%) have NOT talked to a healthcare professional about their experience with subjective cognitive decline.



Roughly 81% of those with memory problems have at least one other chronic condition (defined as arthritis, asthma, COPD, cancer, cardiovascular disease, and diabetes).



More than one third (36%) of those who reported memory problems indicated they live alone.

Figure 4. Percent of North Dakotans with Memory Problems who say it Creates Difficulties and Burden, 2019

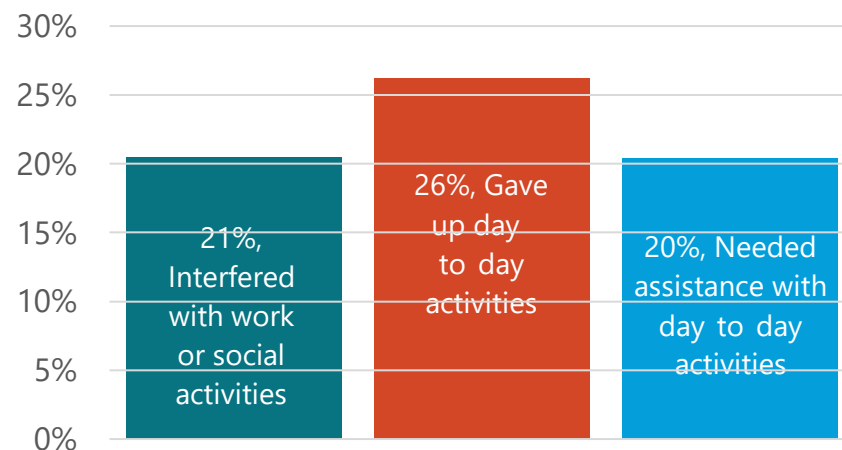


Table 3. Percent of Those Ages 45+ with Subjective Cognitive Decline in North Dakota

Gender		Race		Age					Education				Income Level*					
Men	Women	Native	Non Native	45-59	60-64	65-74	75-79	80+	< Than H.S.	H.S. or G.E.D.	Some Post H.S.	College Grad.	1	2	3	4	5	6
9.5%	6.7%	17.8%	7.8%	6.2%	7.4%	8.3%	9.3%	15.1%	16.9%	9.1%	7.5%	5.9%	17.9%	14.6%	9.0%	7.7%	6.6%	4.9%

Income Levels: (1) <\$15,000; (2) \$15,000 \$24,999; (3) \$25,000 \$34,999; (4) \$35,000 \$49,999; (5) \$50,000 \$74,999; (6) \$75,000+

OPPORTUNITIES TO ADDRESS THE IMPACT OF ALZHEIMER'S DISEASE AND DEMENTIA ON THE HEALTH OF NORTH DAKOTA

A total of five focus groups and 11 key informant interviews were held to assist in identifying need and recommendations for the state. Although these interviews and discussions were focused on identifying opportunities to improve the health and well-being of persons who are at-risk of or diagnosed with Alzheimer's and other dementias and their caregivers, the discussions tended to revolve around supports for caregivers. Broadly, the limited quantitative data that were available and the 33 community members who participated in either focus groups or interviews identified three themes of need.

North Dakota must address, in no particular order, the following community needs in order to achieve the set vision of an inclusive community and health system:

1. Early Detection and Diagnosis

There is a need to create a strong system of early detection and diagnosis through public education campaigns (early warning signs), and training of providers in all healthcare settings.

2. Education and Awareness

There is a need to provide education and awareness campaigns that target the public, persons at-risk of Alzheimer's and other other dementias, providers, and caregivers.

3. Supports for Caregivers

There is a need to identify or develop comprehensive community programs that are well advertised, affordable, and offer a wide range of social supports for caregivers throughout the life course of the disease.

Vision Statement

Create an inclusive community and health system that understands, respects, and supports persons who are at-risk of or diagnosed with Alzheimer's and other dementias, and their caregivers.

Early Detection and
Diagnosis

Education and
Awareness

Supports for
Caregivers

1. Early Detection and Diagnosis

There is a need to create a strong system of early detection and diagnosis through public education campaigns (early warning signs) and training of providers in all healthcare settings.

Early diagnosis was identified as the top priority across the focus groups. It was described as the key factor in a person's ability to receive appropriate services and care as well as to be actively involved in planning and decision making. Early diagnosis was also provided as a way to avoid crisis-driven care, where a person exhibiting symptoms does not receive a diagnosis until after a medical or other crisis (such as wandering or a car accident), delaying access to appropriate services, critical care, and treatment.

The importance of dementia training for primary care physicians (PCPs) for identifying and diagnosing Alzheimer's and other dementias at an early stage was a recurring topic in the focus groups and interviews. A current and former medical professional reported that PCPs did not have enough training to feel confident in providing a diagnosis and that there were not enough specialists, such as gerontologists or neuropsychologists to fill in the gaps. Other focus group participants also identified similar workforce issues, especially in rural areas of the state. Focus group participants emphasized that **many relevant services are not available without a formal diagnosis, making it a fundamental step in providing appropriate care.**

Early diagnosis does not just rest on PCPs. People must first seek out medical assistance to receive a diagnosis, something that often does not happen at an early stage. Seeking care or a diagnosis often occurs late in the disease because of a lack of information or public understanding about what behaviors or symptoms might be related to "normal" aging, compared to symptoms of Alzheimer's and other dementias. The Alzheimer's Association provides "guidance and tools for conducting a [cognitive assessment](#) during a time-limited office visit."³⁷ Participants also identified denial and stigma as factors that may delay a family or individual from seeking out a formal diagnosis. This wait leads to the second theme: education and awareness.

2. Education and Awareness

There is a need to provide education and awareness campaigns that target the public, persons at-risk of Alzheimer's and other other dementias, providers, and caregivers.

Dementia education and awareness were a constant theme, regardless of the topic of discussion at hand. There was wide acknowledgement that people are generally more aware of Alzheimer's and other dementias than in the past as well as the role of the Alzheimer's Association as a source of information. However, that awareness is not enough to translate into knowledge of appropriate care and available services. Focus group participants identified needs for additional

education, training, and awareness for every group providing care, which included medical professionals, family caregivers, people with Alzheimer's and other dementia, long-term care facility staff, and home healthcare workers among others. Participants also expressed the need for education and awareness for people who have not been affected yet by an Alzheimer's diagnosis. Information, related to identifying symptoms of dementia and how they differ from "normal aging," was deemed especially important because having that early information, when not already overwhelmed, could help avoid confusion and denial about the next steps to take, including pursuing a diagnosis.

Three audiences for targeted education included:

1. Medical professionals
2. Family caregivers and people with Alzheimer's and other dementias
3. Other formal care professionals

1. Medical Professionals

The most mentioned need for education and training for medical professionals, especially PCPs, focused on diagnosing Alzheimer's and other dementias and doing so earlier in the disease. Another specific focus was educating medical professionals on how to effectively guide patients and their families toward the next steps for care after there has been a diagnosis. In two focus groups, a cancer diagnosis was provided as a model: once a patient is diagnosed with cancer, wheels are set into motion with a comprehensive care plan that has pre-determined steps and guidance for the patient: an active approach. This method was compared to participant reports of medical professionals handing patients receiving an Alzheimer's diagnosis a pamphlet or suggestion to contact the Alzheimer's Association as the totality of guidance provided: a passive approach. Participants recommended a much more active approach where PCPs encourage and assist families to make the initial contact for services, encourage follow-up visits, and discuss how early services can result in improved outcomes, such as the ability to remain in the home for a longer period of time.

2. Family Caregivers and People with Alzheimer's and Other Dementias

The overwhelming nature of an Alzheimer's or other dementia diagnosis was a constant theme. Even caregivers who received comprehensive information about available services were overwhelmed by the amount of information and confusion about where to start. Representatives from the Alzheimer's Association reported that patients and their families were often not ready to initiate services because of feeling overwhelmed, denial about the need for services at that point in time, or stigma related to asking for help. Information about effective services and how services would change over the life course of the disease were deemed crucial by participants. The discussion, related to education and information, acknowledged that there is a great deal of information available, but it is not always provided in a way that is useful at the time of

diagnosis or soon after. Active guidance through next steps was identified as a need but also reported as not always effective if the family or person with Alzheimer's was not ready. Participants suggested this area is where PCPs or other professionals, such as a case manager, could have a role with scheduling follow-ups and continued discussions to provide continued encouragement and education, and to proactively offer services to families when they are ready.

Although the focus centered on medical and care supports, participants brought up other areas they felt required additional information and education for families and people with Alzheimer's and other dementias. Suggestions included information related to nutrition, strategies to manage behavior changes over the course of the disease, and activities that can be beneficial to people with Alzheimer's. Participants also indicated that families need education and information about financial and legal planning, for example, advance directives, identifying medical and financial power of attorney, and dealing with family assets, such as land ownership. Often these issues come to the forefront when the person with Alzheimer's can no longer make those decisions or a crisis has happened, which can make the process much more difficult.

3. Other Formal Care Professionals

Long-term care facility and home healthcare staff members were also discussed as requiring additional education and training, related to Alzheimer's and other dementias, especially for dealing with common behavioral issues as the disease progresses. Several participants reported feeling that their family member's behaviors were not understood or addressed appropriately in long-term care facilities and said they felt it was because of a lack of education and training in these common behaviors. Involving the Alzheimer's Association into discussions and interventions for behavior in long-term care facilities was discussed as a method of education for staff members. Also, participants in two focus groups indicated that training, related to end-of-life care, especially appropriately timed referrals to hospice care, were of importance.

3. Supports for Caregivers

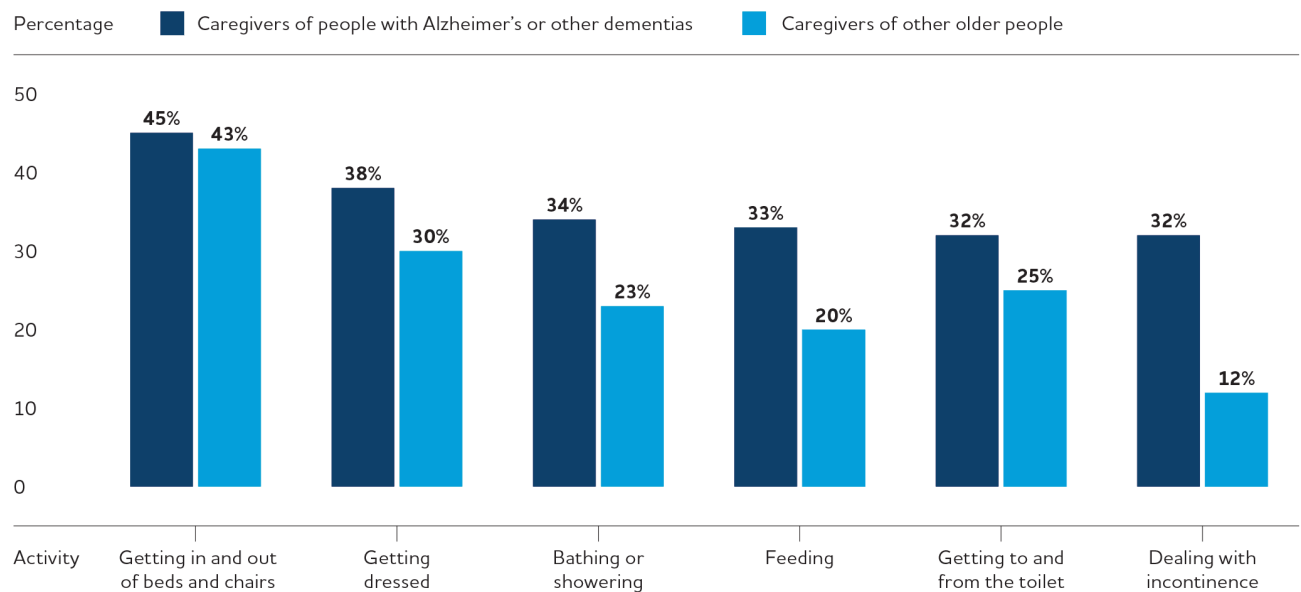
There is a need to identify or develop comprehensive community programs that are well-advertised, affordable, and offer a wide range of social supports for caregivers throughout the life course of the disease.

A consistent message was that family caregivers for people with Alzheimer's are providing an enormous amount of uncompensated care with few supports, breaks, or structured care plan to follow. Providing caregiver assistance was one of the top three priorities as identified by focus group members and primarily focused on services and supports meant to avoid caregiver burnout. Supports exist but can be difficult to navigate, unaffordable, or unavailable.

Nationally, family members and friends provided nearly \$257 billion in unpaid care to people living with Alzheimer's and other dementias in 2020.¹⁰

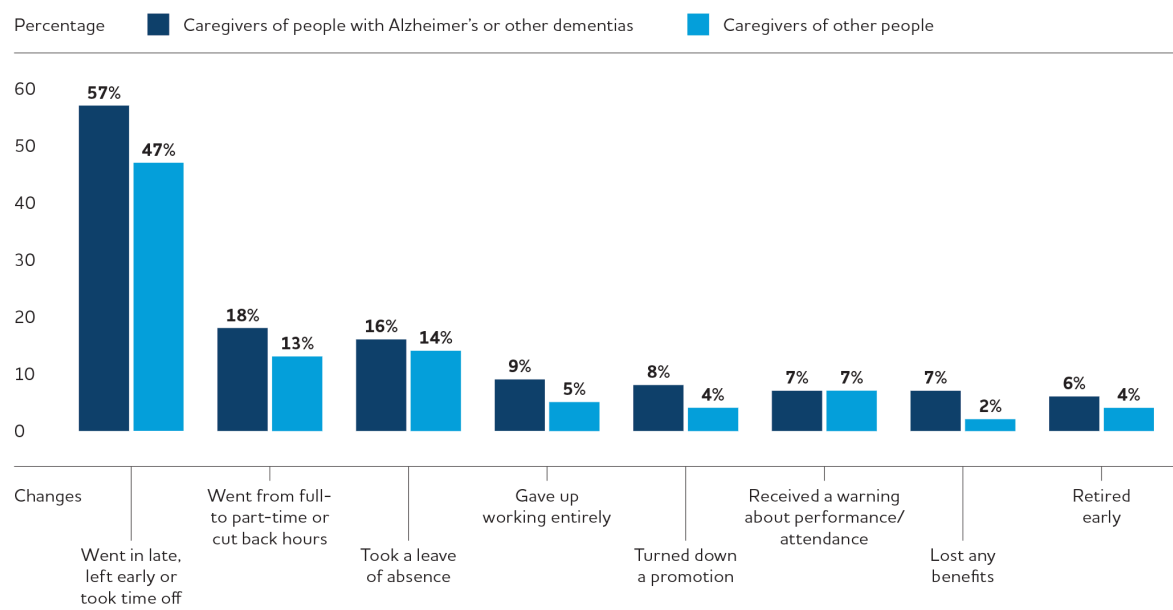
This area of need is consistent with data provided by the Alzheimer’s Association that has identified that a greater percentage of persons, caring for persons with Alzheimer’s and other dementias, are helping with activities of daily living than other persons who are caring for an older family member without Alzheimer’s. See Figure 5.

Figure 5. Proportion of Caregivers of People with Alzheimer’s or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015¹⁰



Caregivers, outside of providing considerable care in the home, are also required to reduce their contributions to the workforce in order to meet the needs of the persons with Alzheimer’s and other other dementias. The Alzheimer’s Association has reported that more than 50% of persons caring for someone with Alzheimer’s or other dementias have had to take time off to provide care. See Figure 6.

Figure 6. Work-Related Changes Among Caregivers of People with Alzheimer’s or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving¹⁰



A paradox of sorts became apparent in discussions about caregiver supports. While many existing support services for caregivers were identified and acknowledged, there was a strong sentiment that they were unutilized (or under-utilized) until there was a crisis, most often, caregiver burnout. This underutilization was often attributed to a lack of information or the overwhelming nature of information mentioned in the previous section as well as actual or perceived costs of supports, especially in-home care. However, in almost every focus group, cultural factors related to notions of self-sufficiency and independence, expectations of the spouse as the most appropriate caregiver, and stigma or resistance to asking for help or feeling like a burden were provided as reasons why existing supports go unused. These reasons were often referred to as “the North Dakota way” or “it’s a North Dakota thing” during discussions. In other words, focus group participants reported that even when caregivers knew of available supports, these cultural norms often prevented or delayed their use, until there was a crisis.

The focus on “crisis-driven care” came up in every focus group and was tied to undesired outcomes for caregivers and people with Alzheimer’s and other dementias, especially caregiver burnout and the inability to keep people in their homes. Much of the related discussion focused on topics already presented: the availability and understanding of the costs and benefits of supports, cultural norms that discourage asking for help, and the sheer overwhelming nature of the disease. One area not previously mentioned was the importance of a preventive approach that recognized people’s physical, mental, emotional, and spiritual needs *before* a crisis hit – a comprehensive, holistic approach to care. According to participants, crisis-driven care meant that appropriate supports and care often came too late to avoid negative outcomes, requiring a focus only on solving the acute situation rather than a prevention or a holistic approach.

Focus group participants had many suggestions and ideas, related to utilization of existing services and the creation of new services, which are briefly described below.

- Increase availability, knowledge of, variety, and use of currently available short-term respite services, both inside and outside of the home.
 - Participants described difficulty in receiving respite care once the person with Alzheimer’s or other dementia had difficulty leaving the home.
- Provide a physical location for what many focus groups referred to as a “one-stop shop” that combined respite, information, and support services for both caregivers and people with Alzheimer’s and other dementia. This idea came up independently (although not every group used the term “one-stop shop”) in almost every focus group when asked to describe their idea of high-quality care for people with Alzheimer’s and their families.
 - Participants envisioned a place where caregivers could receive support and information while their family member participated in appropriate activities.
- Increase access and decrease burdensome paperwork for multi-day respite services.
 - Several participants noted that long-term care facilities can provide multi-day respite services; however, they reported that the option is not widely known, and the intake process is extremely burdensome.
- Increase variety and availability of activities for people with Alzheimer’s and other dementias.
 - For example, focus group members praised the Memory Cafés in Fargo and Grand Forks and recommended more widespread access and availability. In addition, however, participants also noted that these places tend to be religious-based and require a caregiver to be present, inspiring the suggestion for a greater variety and diversity in activities.

Summary of Need

Based on focus groups, key informant interviews, and research on current infrastructure in North Dakota, several assets were identified, but there was also considerable need. Outside of the three key themes of need identified above, concrete and specific needs included:

- Community-based care.
 - More, and affordable, services available for in-home care that support aging in place.
 - Increased access to, and promotion of, memory cafes, hospice, adult day programs, and respite.
- There is a need to identify or develop models for rural and tribal service delivery.
- Need flexibility of service delivery, which includes providing the right services at the right time and in the right location.
- Need to seek opportunities for innovation around telehealth for diagnosis, treatment, and in-home care.
- Across all provider groups and community organizations, we collectively need to support caring for the person and not just seeing and treating the disease.
- Need to be forward thinking and consider the needs of future North Dakotans, including those who may not have family members to care for them, if diagnosed with Alzheimer's or other dementias.

RECOMMENDATIONS FOR NORTH DAKOTA

Healthy People 2030 has a specific goal to “Improve health and quality of life for people with dementia, including Alzheimer’s disease.”⁶ This goal is measured through three specific objectives. See Table 4 for the list of objectives, the baseline, and goal as set by Healthy People 2030.

Table. 4. Healthy People 2030 Goals and Objectives that Relate to Alzheimer’s and Other Dementias⁶

		Baseline	Baseline Year	Goal
Objectives	Increase the proportion of older adults with dementia, or their caregivers, who know they have it.	59.7%	2013-15	
	Reduce the proportion of preventable hospitalizations in older adults with dementia.	23.5%	2013-15	19.1%
	Increase the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider.	45.4%	2015-16	
GOAL	Improve health and quality of life for people with dementia, including Alzheimer’s disease.			

Five Actionable Goals for North Dakota

This state plan has identified five actionable goals, intended to guide action among the wide variety of stakeholders affected by Alzheimer’s and other dementias. Incorporating the needs identified in the previous section, these goals are forward-looking and strengths-based, building on existing resources and capacities. In addition, the goals are aligned with the Healthy People 2030 objectives for Alzheimer’s and other dementias in order to promote the shared vision of creating an inclusive community and health system that understands, respects, and supports persons who are at-risk of or diagnosed with Alzheimer’s and other dementias and their caregivers.

1. Comprehensive Care Over the Full Continuum of the Disease
2. Support for Research
3. Caregiver and Community Education and Supports
4. Workforce Development, Education, and Collaboration
5. Identify and Address Diversity in Research, Supports, and Care Access

Goal 1 - Comprehensive Care Over the Full Continuum of the Disease

Goal 1 recommends a comprehensive approach to care in order to provide **“the right care at the right time”** by building on current services and resources to ensure people diagnosed with Alzheimer’s or other dementia receive appropriate care that prioritizes a holistic, person-centered approach.

Person-centered care is holistic, appropriate, and relevant for the person’s stage of the disease. But more than that, person-centered care views the person diagnosed with Alzheimer’s as more than symptoms to be managed, prioritizing needs related to physical, mental, emotional, and spiritual health. Person-centered care also includes the needs of family and other informal caregivers, recognizing how their roles evolve and often become much more intensive over the course of the disease.

It is also imperative to consider the diversity of people across North Dakota in terms of appropriate person-centered care. This attention includes recognizing and understanding the differential needs and preferences of those who are in our tribal, LGBTQ2S+, refugee, and other marginalized communities as well as those who do not fit a “traditional” family structure with a caregiving spouse and/or child.

Expand the use of currently available options to systematically increase likelihood of appropriate, timely diagnosis.

The findings strongly suggest that increasing early diagnoses is a crucial step in providing appropriate care for people with Alzheimer’s and other dementias. Healthcare facilities have several current tools already available to assist with early diagnosis that can be used more widely. For example, annual Medicare wellness exams are an appropriate starting point, providing an opportunity for yearly cognitive screenings. The currently available Current Procedural Terminology (CPT) code for cognitive assessment and care planning allows for clinical services, related to care planning, safety assessment, and end-of-life planning. These options are currently available yet are underutilized.

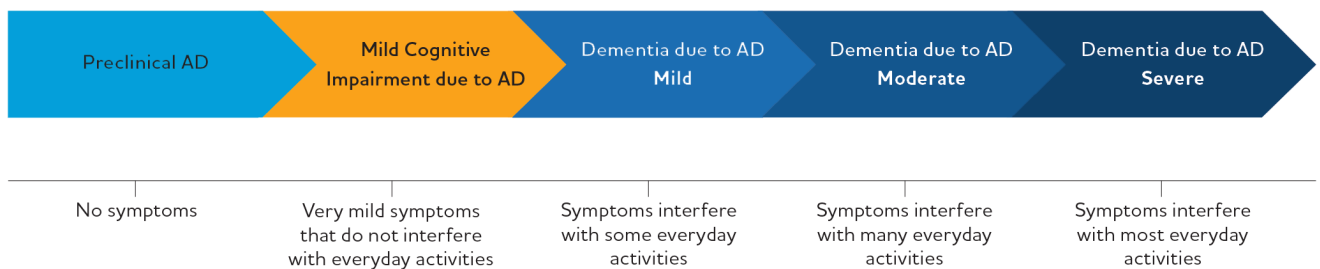
Person-Centered Care Delivery ¹⁰



Develop appropriate care and service options beyond initial diagnosis as patients progress through later stages of the disease.

Early diagnosis was a common topic in our findings; however, clinical services and care for later stages of the disease were not discussed at all, which led to this recommendation. Developing awareness, knowledge, and services appropriate for later stages of the disease to ensure people with Alzheimer’s receive appropriate care will most likely require a combination of developing new services, education, and training as well as building on existing resources. These services could include translating current research into practice, education and training related to appropriate clinical and community services along the life course of the disease, proactively connecting patients and their families to appropriate clinical and community services, and assisting families with issues, such as end-of-life and palliative care.

Figure 7. Alzheimer’s Disease (AD) Continuum ¹⁰



*Although these arrows are of equal size, the components of the AD continuum are not equal in duration.

Build upon and systematize current connections between clinical and community care.

Reports of the ways in which clinical staff connect people diagnosed with Alzheimer’s, and their families, to existing home and community services were varied, demonstrating that there is room to improve the quality and consistency of the coordination between a diagnosis and ongoing clinical care with services outside of the clinical setting. Clinical services can offer not only the initial diagnosis that allows for access to services but also regular follow ups and assessments throughout the course of the disease to ensure ongoing appropriate care. Many stakeholders expressed the need for a care coordinator who would assist families navigate the gap between clinical diagnosis and community services.

Ensure access to appropriate home and community services.

For most people diagnosed with Alzheimer’s and other dementias, home and community-based services are the most appropriate initial option, allowing an individual to remain at home and active in their community for a longer period of time. Benefits of access to consistent and appropriate home and community services include increased quality of life for individuals and families as well as reduced costs to the state and affected families. Services should include dementia-specific practices that address the unique cognitive and behavioral needs, in addition to medical care needs, which often include chronic conditions.

There are currently multiple barriers to accessing home and community services, such as cost, availability in rural areas and perceptions about need or appropriateness, each of which may have different solutions. Modernizing state programs to include key dementia-specific services, such as assistive technology, behavioral supports, home modification, transportation, among others, would help families afford to care for a person living with dementia at home. Ensuring there are sufficient numbers of home and community-based service providers continues to be an issue across the state.

Invest in community supports and programming that support aging in community.

Aging in community is a concept that focuses efforts on accessibility to community resources and services that allow for aging in a person's community of choice, regardless of their level of physical or cognitive ability. These supports may differ, depending on the existing resources, characteristics, and culture of the community. While an exhaustive list is outside of the scope of this plan, supports might include access to financial and medical planning for end-of-life, supports related to transportation and especially decisions about driving, recognizing areas that require a multi-disciplinary approach, and providing a range of supports that are culturally appropriate and address different types of diversity in the community.

Goal 2 - Support for Research

One of the barriers to understanding the needs of North Dakotans with Alzheimer's and other dementias is the lack of statewide data. Understanding the prevalence and incidence of the disease and how it is changing over time can assist in policy planning and resource management. This plan is another area where it is important to pay particular attention to the inclusion of measures, representing the diverse populations in the state, widely defined.

Create and fund an initiative to collect, maintain, and share public data about Alzheimer's and other dementias.

This recommendation is modeled from the existing North Dakota Statewide Cancer Registry. Creating partnerships to collect, analyze, and display information can provide stakeholders with information to understand where the greatest resource needs are and spur policy action. Using other states' examples, Healthy People 2030 objectives, and this report can guide the development of indicators such as prevalence of disease, incidence rates, workforce data, and provision of care (both formal and informal).

Create partnerships and processes for translating research to practice.

Creating robust processes that translate existing research into practice for medical professionals, formal, and informal caregivers that is publicly available and presented in a way that is appropriate for the intended audience can provide support and information of best practices and current findings. Partnering with existing institutions, such as state university gerontology researchers or the CDC's three Public Health Centers for Excellence, related to dementia, can provide opportunities to disseminate research findings to the public without building research capacity from scratch.

Goal 3 - Caregiver and Community Education and Supports

The need to provide information, education, and supports for informal caregivers was the most commonly mentioned concern and need in North Dakota. The recommendations in this section are closely tied to Goals 1, 2, and 4 and have the potential to reduce caregiver stress and burnout, which was communicated as one of the highest priorities in our findings. Goal 3 is primarily focused on the provision of comprehensive, up-to-date information and supports for caregivers and people diagnosed with Alzheimer's and other dementias. Our findings showed that while there is a great deal of information available, it is spread over multiple institutional websites and can be difficult to find, understand, or integrate into the current stage of the disease. The recommendations in this section are also meant to reduce the crisis-driven nature of care reported by many of our stakeholders as well as to recognize and alleviate the enormous amount of unpaid care that is shouldered by families and informal caregivers.

Attending to diversity and cultural considerations, related to caregiver education and support, is important. This training can include (but is not limited to) issues, related to the changing nature of who is providing care (for example, family members vs. home healthcare workers who may be from a different cultural background) and ensuring educational information and supports are culturally competent.

Recognize, understand, and alleviate the burden of unpaid care on family and informal caregivers, especially in light of the Olmstead Decision.

A constant message in our findings was the heavy burden of unpaid care on family members and informal caregivers. Although this care is often willingly provided, there is no question that it takes a heavy toll on people's physical, mental, emotional, and financial health. Many of the recommendations in this document are in line with the Olmstead Decision in terms of prioritizing home and community care. However, prioritizing home and community care must primarily come in the form of increased supports and services rather than continuing to rely on unpaid familial or informal care. In addition, understanding the amount, value, and consequences of current and predicted future levels of unpaid care is crucial for pursuing appropriate policy alternatives.

Review, maintain, and promote an online "one-stop-shop" for information related to Alzheimer's and other dementia care, services, and information in North Dakota.

North Dakota already has a webpage dedicated to sharing information and resources on aging: carechoice.nd.assistguide.net/.²¹ In addition, the Minnesota-North Dakota Chapter of the Alzheimer's Association and AARP North Dakota also provide valuable online resources. However, this issue was raised in almost every focus group, which suggests that the current resources are not widely known or are not meeting people's needs. This outreach will require a collaborative approach because there is not one agency or organization that holds all of the relevant information. This collaboration could also be an opportunity to connect care

coordinators mentioned in Goal 1 with families and caregivers who are searching for information and services. Providing appropriate resources to promote and maintain a comprehensive, user-friendly site is also crucial for this recommendation.

Stakeholders provided many ideas for the types of information that would be helpful in this type of resource including:

- Services and supports for people with Alzheimer’s including cost, location, and availability
- Services and supports for informal caregivers and families of people with Alzheimer’s including cost, location, and availability
- Information about appropriate services along the continuum of the disease
- Information about the importance of early detection and diagnosis along with warning signs and next steps
- Information about dealing with common behavioral and safety issues along the continuum of the disease
- Resources related to financial and end-of-life planning, including how to initiate that conversation

Initiate a public education/awareness campaign about early warning signs and encouraging people to use available supports.

This recommendation focuses on providing information about services in a way that addresses cultural perceptions and norms (the “North Dakota way”) to reduce unnecessary barriers to people receiving appropriate care. Information that emphasizes the ways in which early diagnosis and thus early interventions increase independent (in home) living should be prioritized. The messaging should focus on benefits of early utilization of services and ways those supports can take some of the burden off family and informal caregivers, avoid crisis-driven care, and help people stay in their home and community for as long as possible. This recommendation helps to address the issue of some services remaining underutilized because of perceptions, related to self-sufficiency and appropriateness.

Goal 4 – Workforce Development, Education, and Collaboration

Workforce education, development, and collaboration is a broad goal, focused not only on the medical community but includes those providing direct care, such as in skilled nursing facilities or home health as well as other professionals that may have direct contact with people diagnosed with Alzheimer's and other dementias, such as those working in public safety or public agencies, such as motor vehicle sites. In addition, stakeholders identified collaborating among currently siloed organizations and programs as a way to build on currently available resources. Finally, there is a general need to increase the healthcare workforce more broadly in North Dakota, but a dire need also exists to increase the number of providers in the state who serve persons who have Alzheimer's and other dementias.

Build a healthcare workforce that serves people with Alzheimer's and other dementias.

Increasing the number of healthcare providers who are trained to serve people with Alzheimer's and other dementias is imperative to meeting most of the other goals and recommendations in this document. The dearth of healthcare providers with knowledge and expertise in Alzheimer's and other dementias across the care spectrum was a widespread concern, expressed by stakeholders. Rural areas are especially affected, but it is a statewide issue. It is a complicated problem with many interrelated factors, related to training and credentials, pay and reimbursement, recruitment and retention. Having an adequate, skillful workforce not only will help people with Alzheimer's and other dementias get appropriate and up-to-date care but also could help alleviate the high rate of uncompensated care, provided by informal caregivers. Creating and increasing the workforce should also not be limited solely to traditional licensed medical professionals but should include the entire care team to include community health workers as well as other community-based services that support and prolong independence. A final consideration, when growing workforce, is to make efforts to educate, recruit, and retain a diverse workforce capable of providing equitable and culturally-relevant care. The importance of creative and collaborative solutions to drastically increase the trained workforce cannot be understated.

Provide widely available education and information on diagnosis, referral, and disease management for healthcare workers and community-based service providers.

This recommendation focuses on those directly providing care in order to increase their understanding and identification of Alzheimer's and other dementias, the importance of early detection, how to provide appropriate referrals for services and support, and how to assist and guide patients and their families in disease management. Healthcare workers and organizations can provide an essential, trusted link to services that can provide information, encouragement, and systematic follow-up. Stakeholders often envisioned using a cancer diagnosis model where a diagnosis would be accompanied by a care plan. This recommendation is not limited to early diagnosis and is especially important for later stages of the disease continuum, when behavioral

and other issues need to be planned for and dealt with at home, in skilled nursing facilities, and in the community.

There is also a specific need to develop new continuing education opportunities for those already working in care for persons with Alzheimer's and other dementias to keep skills and knowledge up-to-date with new evidence and advances in geriatrics care.

Encourage and facilitate conversation, collaboration, and innovation between organizations.

Information, research, and best practices are often siloed in individual organizations. Encouraging and facilitating collaboration between public, private, and nonprofit organizations could lead to innovation that does not require building services, tools, or practices from scratch. This recommendation does not only include prioritizing conversations, related to Alzheimer's and other dementias among organizations directly involved in care, but should also include professional organizations, such as the North Dakota Medical Association.

Goal 5 - Identify and Address Diversity in Research, Supports, and Care Access

One of the limitations of the process of creating this plan was the difficulty in including diverse experiences from traditionally under-represented and marginalized groups. Thus, Goal 5 recommends identifying and integrating perspectives from groups and cultures that are currently not represented in the plan and are often under-represented in discussions, concerning Alzheimer's and other dementias. This recommendation includes but is not limited to people of non-White racial and ethnic backgrounds, LGBTQ2S+, Indigenous, migrant, immigrant, and refugee communities. While recommendations, related to diversity and inclusion, have been added to several of the previous goals, they are predicated on this goal to include those communities and groups in order to understand their needs and how they may be different from those who were involved in providing information for this report.

CONCLUSION

This state plan was developed in partnership with community stakeholders, caregivers, representation from Medicaid, medical and community care providers, state and national organizations, and associations dedicated to improving the health and well-being of those who are aging as well as those with Alzheimer's and other dementias. Although there were several opportunities to improve care provision and community program access, partners and stakeholders also identified assets in the state and illustrated a strong commitment to work together in order to achieve a shared vision:

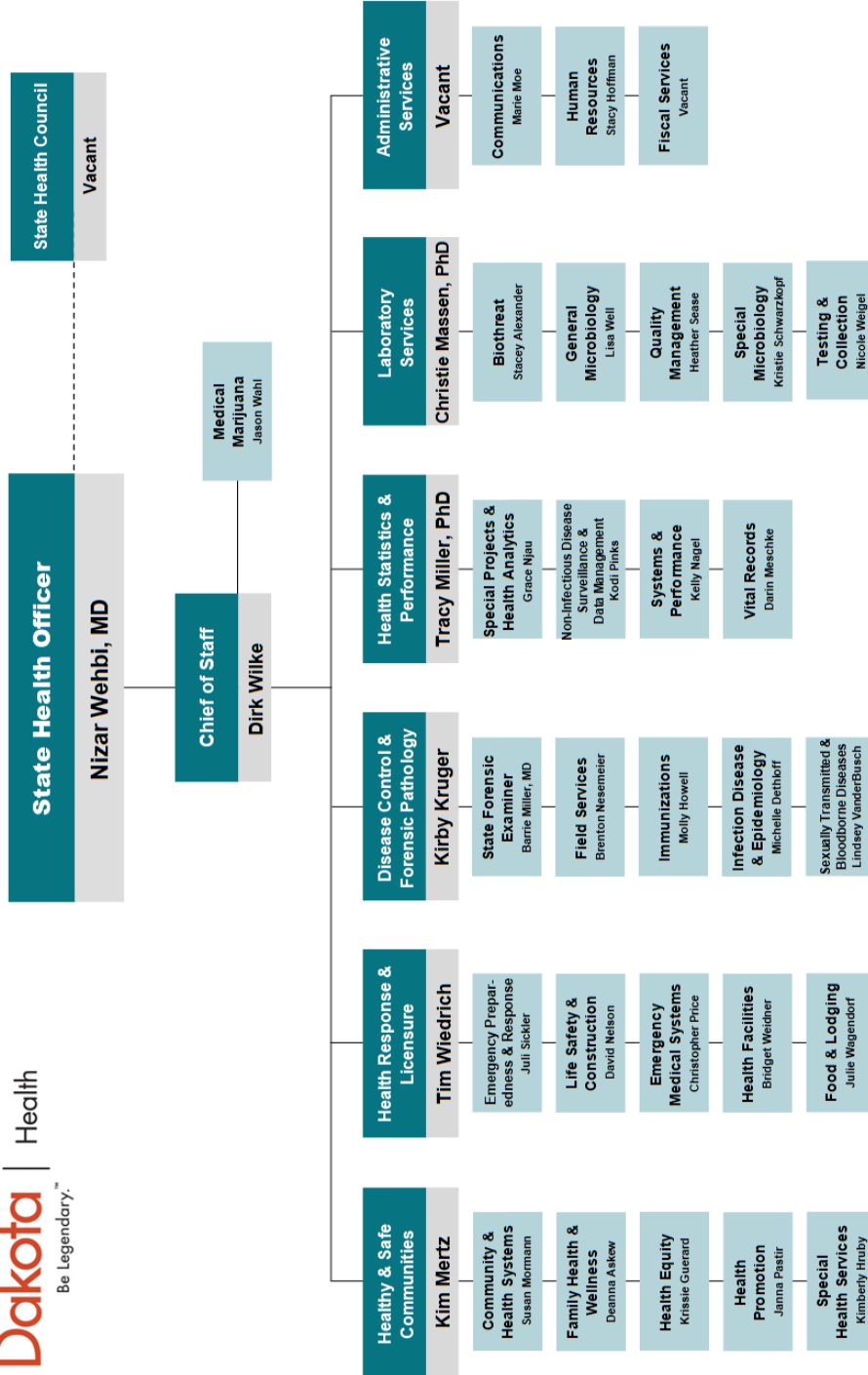
To create an inclusive community and health system that understands, respects, and supports persons who are at-risk of or diagnosed with Alzheimer's and other dementias, and their caregivers.

CITATIONS

1. Alzheimer's Association. (2018, December 6). Alzheimer's Disease Facts and Figures. [https://www.alz.org/media/Homeoffice/Facts and Figures/facts-and-figures.pdf](https://www.alz.org/media/Homeoffice/Facts%20and%20Figures/facts-and-figures.pdf)
2. Montana Alzheimer's/Dementia Work Group. (December, 2016). MONTANA Alzheimer's and Dementia State Plan. <https://mtalzplan.org/state-plan-2/>
3. Lin, S. & Marcus Lewis, F. "Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future." *The Gerontologist* 55, no. 2 (2015): 237-244.
4. Borson, S. & Chodosh, J. "Developing Dementia-Capable Health Care Systems: A 12-Step Program." *Clinics in geriatric medicine* 30, no. 3 (2014): 395-420.
5. Dementia Friendly America® About DFA. (2018, December 11). <https://dfamerica.org/what-is-dfa/>
6. Healthy People 2030. <https://health.gov/healthypeople/objectives-and-data/browse-objectives/dementias>
7. Centers for Disease Control and Prevention. (2019, September). Leading Causes of Death – Females – by Race and Hispanic origin – United States, 2016. www.cdc.gov/women/lcod/2016/byraceandhispanic/index.htm
8. Yang H.D., Kim D.H., Lee S.B., & Young L.D.. History of Alzheimer's Disease. *Dement Neurocogn Disord.* (2016): 15(4):115-121. doi:10.12779/dnd.2016.15.4.115
9. Queensland University and Technology. (n.d.). Cultural and religious issues. <https://research.qut.edu.au/objectiontocoronersautopsy/cultural-and-religious-issues/>
10. Alzheimer's Association. (2021). Alzheimer's Disease Facts and Figures: Alzheimer's Association. <https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>
11. Centers for Disease Control and Prevention. (2020, September). Alzheimer's Disease and Healthy Aging. *Healthy Brain Initiative Road Map for Indian Country.* <https://www.cdc.gov/aging/healthybrain/indian-country-roadmap.html>
12. Alzheimer's Association. (2021). Serving African American Families. https://www.alz.org/national/documents/aoagrant_kts_aa.pdf
13. Cann, K. Candi. (2015). Grief and Cultural Competence: Hispanic, African American and Jewish Traditions. Funeral Course. <https://funeralcourse.com/wp-content/uploads/2015/09/3Hour-Grief-Course.pdf>
14. Cox C. & Monk A. (1993). Hispanic culture and family care of Alzheimer's patients. *Health Soc Work.* 18(2):92-100. DOI: [10.1093/hsw/18.2.92](https://doi.org/10.1093/hsw/18.2.92)
15. Jang Y., Yoon H., Park N.S., Rhee M.K., & Chiriboga D.A. Asian Americans' concerns and plans about Alzheimer's disease: The role of exposure, literacy and cultural beliefs. *Health Soc Care Community.* (2018). 26(2):199-206. doi:[10.1111/hsc.12509](https://doi.org/10.1111/hsc.12509)
16. Alzheimer's Association. (2021). Strengthening Community-Based Services for Asian American and Pacific Islanders Affected by Dementia. <https://www.alz.org/national/documents/strengthening-community-based-services-asian.pdf>
17. North Dakota Legislative Council staff for the Long-Term Care Committee. (2007, July). North Dakota State Plan for Alzheimer's and Dementia. <https://www.legis.nd.gov/assembly/60-2007/docs/pdf/99045.pdf>
18. North Dakota Human Services. (2021). North Dakota State Plan on Aging. <http://www.nd.gov/dhs/info/pubs/docs/aging/state-plan-on-aging.pdf>
19. Alzheimer's Impact Movement – Alzheimer's Association. (2021, March). State Alzheimer's Disease Plans. <https://alzimpact.org/media/serve/id/5d23af19258fb>

20. Alzheimer's Association. (2021). State Overview: North Dakota. <https://www.alz.org/professionals/public-health/state-overview/north-dakota>
21. [carechoice.nd.assistguide.net/](https://www.carechoice.nd.assistguide.net/)
22. Alzheimer's Association. (2021). North Dakota Dementia Care Services Programs. https://www.legis.nd.gov/assembly/67-2021/testimony/SAPPR-1012-20210311-8699-F-WEGNER_NIKKI.pdf
23. United State Department of Justice Civil Rights Division. (n.d). Olmstead: Community Integration for Everyone. https://www.ada.gov/olmstead/olmstead_about.htm
24. Alzheimer's Association. (2021). What is Alzheimer's Disease? <https://www.alz.org/alzheimers-dementia/what-is-alzheimers>
25. Centers for Disease Control and Prevention. (2020, October 26). Alzheimer's Disease and Healthy Aging. <https://www.cdc.gov/aging/aginginfo/alzheimers.htm>
26. Alzheimer's Association. (2021). Causes and Risk Factors for Alzheimer's Disease. <https://www.alz.org/alzheimers-dementia/what-is-alzheimers/causes-and-risk-factors>
27. Alzheimer's Association. (2021). 10 Warning Signs of Alzheimer's. <https://www.alz.org/media/Documents/alzheimers-dementia-10-signs-worksheet.pdf>
28. Alzheimer's Association. (2021). 10 Early Signs and Symptoms of Alzheimer's. https://www.alz.org/alzheimers-dementia/10_signs
29. Mayo Clinic. (2019, April 19). Diagnosing Alzheimer's: How Alzheimer's is diagnosed. <https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/in-depth/alzheimers/art-20048075>
30. Alzheimer's Association. (2021). How is Alzheimer's Disease Diagnosed? <https://www.alz.org/alzheimers-dementia/diagnosis>
31. The [Alzheimer's Association](#)
32. The [National Institute on Aging](#)
33. The [Centers for Disease Control and Prevention](#)
34. The [North Dakota Department of Health](#)
35. The American Geriatrics Society. (2016, May). Projected Future Need for Geriatricians. <https://www.americangeriatrics.org/sites/default/files/inline-files/Projected-Future-Need-for-Geriatricians.pdf>
36. Alzheimer's Association. (2019). Cognitive decline in North Dakota. https://alz.org/media/Documents/North-Dakota-2019-Cog-BRFSS-Fact-Sheet.pdf?_gl=1*sxpnja*_ga*MTkyNjgwNDg1NS4xNjI2NzI0NzU5*_ga_9JTEWVX24V*MTYyNjc5NDk2Mi4yLjEuMTYyNjc5NTA2NC4w&_ga=2.139915443.1670878047.1626724759-1926804855.1626724759
37. Alzheimer's Association. (2021). Cognitive Assessment. <https://www.alz.org/professionals/health-systems-clinicians/cognitive-assessment>
38. North Dakota Department of Health. (2020). September Organizational Chart. https://www.health.nd.gov/sites/www/files/documents/Webpage%20Updates/Org_Chart_9_22_21.pdf

Appendix A: North Dakota Department of Health Organizational Chart 38



Appendix B: List of Internal Development Team, Advisory Group Members, and Stakeholders

Stakeholder and colleagues were identified as a member of one of three groups:

- Internal state plan development team
- Advisory group
- Stakeholder group

Internal State Plan Development Team

- Melissa Kainz, Community Clinical Coordinator, North Dakota Department of Health
- Janna Pastir, Director of Health Promotion, North Dakota Department of Health
- Beth McMullen, Vice President of Gov. Affairs, Alzheimer's Association
- Josh Ney, Manager of State Affairs, Alzheimer's Association
- Christopher Prosch, Director of Public Policy for North Dakota, Alzheimer's Association
- Laura Hand, Associate Professor of Political Science, Public Administration and Masters of Public Health, University of North Dakota
- Shawnda Schroeder, Associate Director of Research and Evaluation, University of North Dakota
- Rebecca Quinn, Program Director, University of North Dakota
- Blake Griener, Research Specialist, University of North Dakota
- Gretchen Dobervich, Public Health Policy Manager, North Dakota State University
- Matthew Campion, Masters Student, University of North Dakota
- Amber Buzick, Masters Student, University of North Dakota

Advisory Group

The role of the advisory group was to inform the internal development team and to review the data, making recommendations for further data review or additional analyses.

- Melissa Kainz, Community Clinical Coordinator, North Dakota Department of Health
- Janna Pastir, Director of Health Promotion, North Dakota Department of Health
- Beth McMullen, Vice President of Gov Affairs, Alzheimer's Association MN-ND Chapter
- Josh Ney, Manager of State Affairs, Alzheimer's Association MN-ND Chapter
- Gary Schwartz, Professor, Department Chair Population Health, University of North Dakota
- Colin Combs, Professor, Department Chair, Biomedical Sciences, University of North Dakota
- Donald Jurivich, Professor, Department Chair, Geriatrics, University of North Dakota
- Shelly Peterson, Executive Director, North Dakota Long Term Care Association
- Nancy Nikolas-Maier, Director of Aging Services, North Dakota Department of Human Services

- Josh Askvig, State Director, AARP North Dakota
- Bruce Murry, Executive Director, North Dakota Association of Community Providers
- Gunjan Manocha, Assistant Professor, Geriatrics, University of North Dakota
- Nikki Wegner, ND Program Director, Alzheimer's Association MN-ND Chapter
- Chris Prosch, Public Policy Director, North Dakota Alzheimer's Association
- Michelle Lauckner, Quality Improvement Specialist, Great Plains Quality Improvement Specialist/Quality Health Associates of North Dakota
- Jayme Steig, Quality Health Associates, North Dakota Department of Health

Stakeholders: Focus Groups and Key Informant Interviews

These individuals included caregivers, providers, social workers, tribal health representatives, educators, persons with lived experience, insurers, and more. These individuals participated in focus groups and key informant interviews anonymously. To protect their identity, below is the list of organizations or the key perspectives they represented.

Family Members/Caregivers
 Direct Service Providers
 State Agency Personnel
 Older Adult & Caregiver Advocacy Organizations

Medical & Clinical Practitioners
 Community Educators
 Church Pastors
 Alzheimer's Association

Appendix C: Data Sources

Alzheimer's Disease Facts and Figures, 2021, 2020, and 2019

Alzheimer's Association

This resource provides data tables and figures around Alzheimer's and dementia to include social, personal, and economic impacts for the person and their caregivers.

Available at:

1. [alz.org/media/documents/alzheimers-facts-and-figures.pdf](https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf) (2021)
2. [alz.org/aaic/downloads2020/2020 Facts and Figures Fact Sheet.pdf](https://www.alz.org/aaic/downloads2020/2020_Facts_and_Figures_Fact_Sheet.pdf) (2020)
3. [alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf](https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf) (2019)

Alzheimer's Disease and Healthy Aging, 2021

Centers for Disease Control and Prevention

Data are provided at the state and county level on a variety of risk-factors and health behaviors focused on, and related to, caregiving and persons with Alzheimer's and other dementias. Data are compiled from a variety of sources including the Behavioral Risk Factor Surveillance System.

Available at: [cdc.gov/aging/index.html](https://www.cdc.gov/aging/index.html)

Care Interventions for People Living with Dementia and Their Caregivers, 2020

Butler M, Gaugler JE, Talley KMC, et al. (2020)

A detailed and summarized source of data surrounding intervention-based care for individuals with Alzheimer's and dementia. Studies conducted to understand evidence based interventional care for Alzheimer's impacted individuals.

Available at: effectivehealthcare.ahrq.gov/products/care-interventions-pwd/report

Fact Sheets and Information, 2021

Alzheimer's Foundation of America

A plethora of data related to dementia warning signs, fall prevention, tips for traveling, care transitions, etc. Data is reported using specific webpage-based information.

Available at: [alzfdn.org/caregiving-resources/fact-sheets-information/](https://www.alzfdn.org/caregiving-resources/fact-sheets-information/)

Healthy People 2030, 2021

US Department of Health and Human Services

The three measures collected around Alzheimer's and other dementias include: the proportion of older adults with dementia, or their caregivers, who know they have it; the proportion of preventable hospitalizations in older adults with dementia; and, the proportion of adults with subjective cognitive decline who have discussed their symptoms with a provider.

Available at: [health.gov/healthypeople/objectives-and-data/browse-objectives/dementias](https://www.health.gov/healthypeople/objectives-and-data/browse-objectives/dementias)

MedlinePlus, 2021

US National Library of Medicine

A plethora of data including Alzheimer's disease-based symptoms, diagnosis, treatment and therapies, and genetics, reported online with detailed descriptions and infographics.

Available at: medlineplus.gov/alzheimersdisease.html#cat11

National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. Healthy Aging Data, 2021

Centers for Disease Control and Prevention

National and state-specific data involving cognitive decline/memory loss, functional difficulties, and needed assistance, among older adults, compared and reported using figures constructed using Behavior Risk Factor Surveillance System data.

Available at: cdc.gov/aging/agingdata/index.html

National Institute on Aging, 2021

A new website designed to educate individuals about Alzheimer's disease, provide tips and resources for caregivers and joining clinical trials to assist in advancement of treatment and prevention of dementias presented using an informational public webpage.

Available at: nia.nih.gov/

Publications - About Alzheimer's, Other Dementias and Related Conditions

Alzheimer's Association

A wide range of infographic-based resources providing dementia related data.

Available at: alz.org/help-support/resources/publications

Appendix D: Focus Group Questions

Before asking questions:

- Introduce focus group moderators(s)
- Allow focus group participants to introduce themselves
- Review consent letter / purpose of the research / remind of recording
- Review group protocol (using raise hand button, not interrupting, etc.)
- Any questions before we start?

The focus group questions will be informed by the responses from key informant interviews. We will file an addendum once the focus group questions have been created. They will focus on specific identified priorities and actions from the interviews, as well as any informational gaps we have identified.

1. Detailed introductions? Name, organization/role, experience with Alzheimer's, why decided to participate today.
2. From your point of view, how would you envision high quality care over the course of the disease? We'll talk about early, mid & late stages.
 - a. Early
 - b. Mid
 - c. Late
3. What resources are working well?
4. What resources are not working well or are missing / difficult to use?
 - a. In a perfect world, how would those work differently?
5. For those of you with caregiving responsibilities, could you describe a typical day? How has that changed over the course of your loved one's progression through the disease?
 - a. What resources have you used? What has been helpful / not helpful? If you could change something about it what would it be?
 - b. At what point did you decide you needed those services?
 - c. What services do you wish you had right now?
6. Providers – what resources for referrals or other information do you provide? What do you find helpful? What do you wish you had?
7. What do you think should be the highest priorities for caring for people with Alzheimer's?
 - a. Rank order? (maybe add their priorities on the fly?) – can have someone working on that while another question is being asked
 - i. Early diagnosis, referrals, and planning
 - ii. Education / Information
 - iii. Healthcare provider training
 - iv. Aging in place

- v. Supporting independence through course of disease
 - vi. Caregiver assistance (respite, case management)
 - vii. Availability of services / geographic access
 - viii. Cost of care and services
 - ix. Collaboration between related organizations
 - x. Long-term care
 - b. Is there anything we missed that we should talk about?
8. What are some suggestions of actions or services that you think would help with Alzheimer's care in North Dakota?
9. What would you want policy makers and decision makers to know about your experience with Alzheimer's?

Poll: What do you think should be the highest priorities for caring for people with Alzheimer's?

Choose your top 4

- Early diagnosis, referrals, and planning
- Education / Information
- Healthcare provider training
- Aging in place
- Supporting independence through course of disease
- Caregiver assistance (respite, case management)
- Availability of services / geographic access
- Cost of care and services
- Collaboration between related organizations
- Long-term care

Appendix E: Key Informant Interview Protocol

Name of interviewer: _____ Date: _____

Before asking questions:

- Introduce interviewer(s)
- Review consent letter / purpose of the research / ask permission to record
- If there are any questions you would prefer not to answer, you can “pass” and we’ll move on to the next. You can end the interview at any time.
- Any questions before we start?

Key Informants – Individuals who are not directly involved with patient care/ caregiving/service provision

1. Could you tell me about your organization’s role in Alzheimer’s care?
 - a. What is your role within the organization?
 - b. Who is the primary target service group?
 - c. How does your organization’s role or services change over the course of the disease for an individual using your services?
2. How would you describe a typical (day/experience/appointment)?
3. How has your organization’s role / services changed over time?
4. What do you think is currently working well for those diagnosed with or at risk for Alzheimer’s and their families?
 - a. What contributes to this success? Why do you think this is working well?
 - b. How do you define success / know it is working well?
5. What do you think is currently not working well?
 - a. Why do you think this is not working well? Are there ways this could be improved?
 - b. What barriers are there to improving this issue?
6. Are there any current opportunities that are under-utilized or you feel could be leveraged? (low-cost, easy)
7. Are there services or resources that are missing?
8. Of the needs you have mentioned how would you prioritize them? How feasible / important is each?
9. What do you think decision makers should know about Alzheimer’s care in the state?
10. Do you have any other suggestions for policies/actions to propose?
11. Do you have ideas of other people we could contact for information about Alzheimer’s care in ND?
12. If we have additional questions at a later time, would it be ok to contact you again?

Key Informants – Individuals directly involved with patient care / caregiving / service provision

1. Could you tell me about your caregiving role?
 - a. How has your loved one's / patient's needs changed over the course of the disease? How has that affected your role?
2. How would you describe a typical day involving your caregiving duties?
 - a. Are there skills you've had to acquire? How did you do that? Have they changed over time?
3. In your experience, are there resources or services that are currently working well for you or have worked well in the past?
 - a. What contributes to this success? Why do you think this is working well?
 - b. How do you define success / know it is working well?
4. In your experience, are there resources or services that are not currently working well for you or have not worked well in the past?
 - a. Why do you think this is not working well? Are there ways this could be improved?
5. How would you describe quality care for someone diagnosed with Alzheimer's? Have you encountered barriers to providing what you would consider to be good care?
6. What are your priorities for your loved one / patient with Alzheimer's? (for example, keeping them at home, etc.)
7. Are there services or resources that are missing or difficult to use?
8. How has being a caregiver affected you personally / professionally?
9. How would you describe your knowledge / awareness of Alzheimer's disease, the course of the disease and/or available resources before you became a caregiver?
10. What would you like decision makers to know about your experience with Alzheimer's care?
11. Do you have any other suggestions for policies/actions to propose?
12. Do you have ideas of other people we could contact for information about Alzheimer's care in ND?

Appendix F: 2007 State Plan for Alzheimer's Disease

99045

Prepared by the North Dakota Legislative Council
staff for the Long-Term Care Committee
July 2007

DEMENTIA-RELATED SERVICES - BACKGROUND MEMORANDUM

The 2007 Legislative Assembly approved House Concurrent Resolution No. 3022 ([attached as an appendix](#)) providing for a Legislative Council study of the availability of and future need for dementia-related services and funding for programs for individuals with dementias.

PREVIOUS STUDIES

The 1995-96 Budget Committee on Home and Community Care studied the continuum of care for North Dakotans with Alzheimer's and related dementias and the needs of caregivers and families of patients with Alzheimer's and related dementias.

The committee recommended House Bill No. 1037 which required the Department of Human Services to establish pilot projects to meet the service needs of the Alzheimer's and related dementia population. The pilot projects explored the financial and service viability of converting existing nursing facility or basic care bed capacity to a specific service environment that targets this population. The committee also recommended House Concurrent Resolution No. 3003 directing the Legislative Council to monitor the implementation of the projects developed by the Department of Human Services relating to converting existing bed capacity for use by Alzheimer's and related dementia persons.

The 1997-98 Budget Committee on Long-Term Care monitored the implementation of the Alzheimer's and related dementia population projects. The committee heard information from the task force on long-term planning and learned that, due to delays in the startup of the pilot projects, it was not possible to fully evaluate the effectiveness of the pilot projects during the 1997-99 biennium.

The committee recommended Senate Bill No. 2034 to authorize the Department of Human Services to continue the approved Alzheimer's and related dementia population pilot projects into the 1999-2001 biennium and required the department to monitor and report on the progress of the pilot projects. In addition, the committee accepted other recommendations of the task force, including:

1. The Department of Human Services allow other entities the opportunity to develop alternative residential services for Alzheimer's and related dementia populations or other populations that meet quality and financial standards established by the department.
2. Funding for these projects come from the existing appropriations for the Medicaid home and community-based services waiver or the expanded service payments for elderly and disabled (SPED) program. The number of projects was limited by the number of available home and community-based services waiver slots approved by the federal

government, the cost neutrality requirement contained in the home and community-based services waiver, and the total appropriation for the expanded SPED program.

The 1999-2000 interim Budget Committee on Institutional Services received the final report from the Department of Human Services on the progress of the Alzheimer's and related dementia pilot projects. The committee learned that based on the department's review of the Baptist Home in Kenmare and with the approval of three additional units, the Alzheimer's and related dementia pilot project accomplished the goal set forth in the original legislation. The report indicated the facility in Kenmare provided appropriate and adequate care to its residents with Alzheimer's and related dementia. The payment rate for the Medicaid recipients was \$67.26 per day and the room and board rate was \$12.10 per day. The total cost to a Medicaid recipient eligible for the home and community-based services waiver was \$79.36 per day or \$15.05 per day less than the services of a similar nature in a nursing facility of \$94.41 per day.

Senate Concurrent Resolution No. 4027 (2005) provided for a study of the need for dementia-related services, standards, and practices for caregivers and a review of the legal and medical definitions used for dementia-related conditions and the funding for programs and services for individuals with dementias. By Legislative Council directive, the scope of the study was limited to a review of the legal and medical definitions used for dementia-related conditions. The study was assigned to the **2005-06 Judicial Process Committee**. The committee made no recommendation as a result of its study of the legal and medical definitions used for dementia-related conditions.

ALZHEIMER'S DISEASE DEMONSTRATION GRANT

In 2004 the Department of Human Services received a three-year federal Alzheimer's disease demonstration grant to expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and caregivers, as well as to improve the responsiveness of the home and community-based care system for persons with dementia. The program focuses on serving hard-to-reach and underserved individuals with Alzheimer's disease or related dementia. The grant award was \$261,150 for each year of the three-year grant. Since not all the funds were spent, the department requested and received a one-year extension of the grant through June 30, 2008. The North Dakota program focuses on building an alliance between the medical community, community services network, and the North Dakota family caregiver support program to increase early dementia

identification, treatment options, and caregiver respite. The grant requires a 25 percent nonfederal match the first year, 35 percent the second year, and 45 percent the third year. The Dakota Medical Foundation has provided a portion of the match for each of the three years of the project with the remainder being provided by the contractors who are providing the services funded by the grant.

REAL CHOICE SYSTEMS CHANGE GRANT

In September 2004, the Department of Human Services received a three-year \$315,000 Real Choice systems change grant to provide a single point of access to long-term support and care services for the elderly and individuals with disabilities. The Department of Human Services contracted with the North Dakota Center for Persons with Disabilities in Minot State University to conduct the project. The project, known as the Real Choice Systems Change Grant - Rebalancing Initiative, is working to develop a plan for rebalancing funds between long-term care services and those services provided in home or community settings. The project is also involved in the development of a new system for providing a single point of entry for services for the elderly and individuals with disabilities who are considering long-term care and home and community-based services. The project has brought together representatives from public and private organizations involved in assuring that the North Dakota elderly and individuals with disabilities have options and access to the continuum of long-term care services in the state.

SINGLE POINT OF ENTRY

Senate Bill No. 2070, approved by the 2007 Legislative Assembly, appropriates \$40,000 from the

general fund to match \$800,000 of federal funds which if approved by the federal government will allow the Department of Human Services to establish or contract for an Aging and Disability Resource Center to provide a single point of entry to North Dakota's continuum of care services for the elderly and disabled.

STUDY PLAN

The committee may wish to proceed with this study as follows:

1. Gather and review information on Alzheimer's and dementia-related services available in the state, including in-home and residential services, the cost of these services, and funding available to assist in paying for these services.
2. Receive information from interested persons, including the North Dakota Long Term Care Association and the Alzheimer's Association regarding the availability of dementia-related services in this state and the need for and projected need for additional services and funding for individuals with dementia.
3. Receive information from the Department of Human Services and the North Dakota Association of Counties regarding programs and services for individuals with dementia and related funding.
4. Develop committee recommendations and prepare any legislation necessary to implement the committee recommendations.
5. Prepare a final report for submission to the Legislative Council.

ATTACH:1