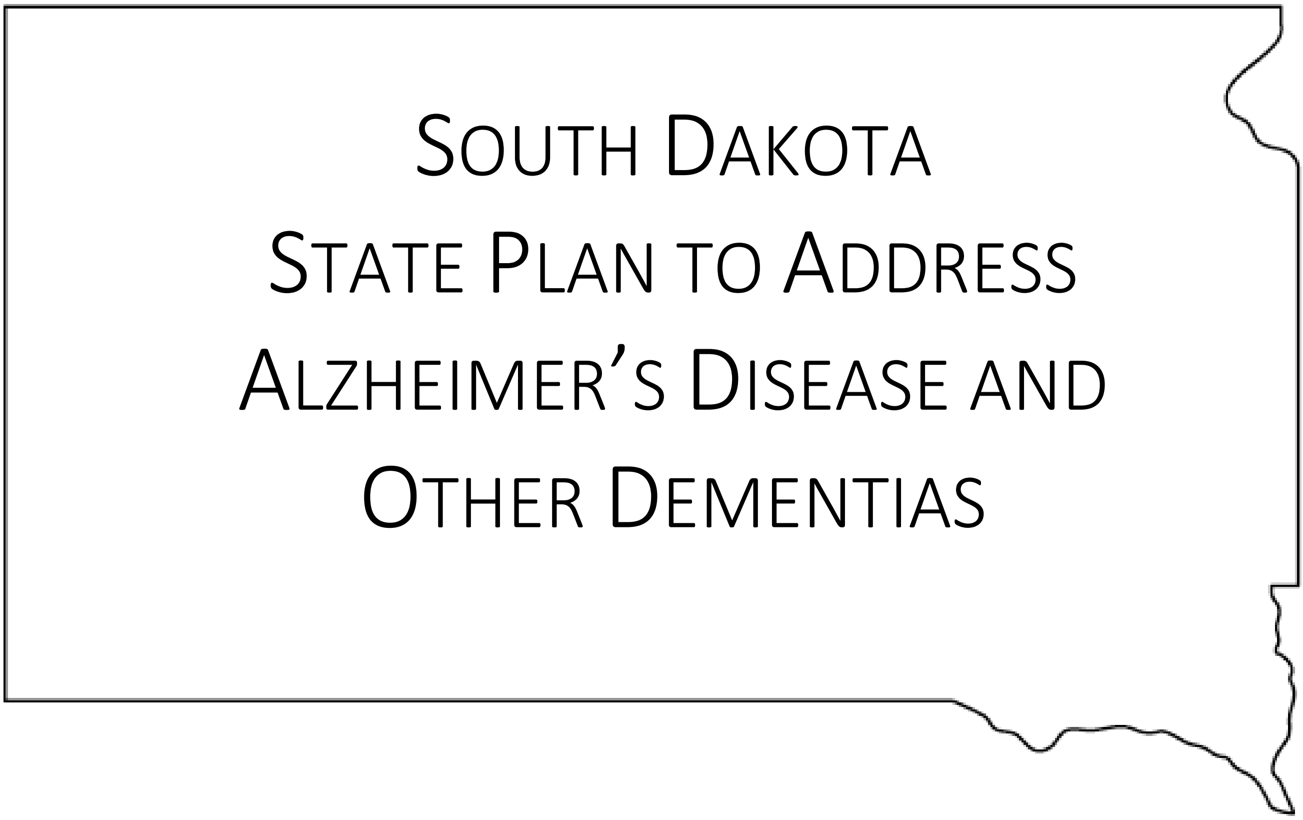

South Dakota State Plan to Address Alzheimer’s Disease and Other Dementias

South Dakota Alzheimer’s Disease and Other Dementias State Plan Work Group

DECEMBER 2018

Made Possible by The Alzheimer’s Association’s South Dakota Chapter and
South Dakota Community Foundation

TO THE PEOPLE OF SOUTH DAKOTA:

> *"This disease turned our lives upside down. Alzheimer's is not just impacting me, but also my husband, our children and their kids. It's robbed me of my livelihood, my independence, and certainly, my memories."*

That is how a South Dakotan living with Alzheimer's described the effects of this disease on a person, family and community. It is a stark example of the need for a statewide call to action.

The numbers are staggering. In South Dakota alone, 17,000 people are living with an Alzheimer's diagnosis. More than 38,000 people are serving as their unpaid caregivers. South Dakota has the third highest death rate in America due to Alzheimer's. But the numbers do not tell the whole story. Across South Dakota, families are struggling with the stress of caring for loved ones who are experiencing the debilitating effects of Alzheimer's and other diseases that cause dementia. In addition, it impacts friends, neighbors and communities in ways that cannot be underestimated.

To address this issue, a voluntary group of stakeholders – health care professionals, state agency officials, legal and financial experts, professional care providers and family caregivers – came together to form the South Dakota Alzheimer's Disease and Other Dementias Work Group. Over the ensuing months, this group collected and analyzed data through a statewide needs assessment, held 15 town hall discussions, conducted research, and examined best practices in dementia care. This thorough evaluation by the Work Group culminated in the recognition of priority areas and development of action steps to prepare South Dakota to meet the immediate and future needs of people affected by these devastating diseases.

South Dakota's State Plan to Address Alzheimer's Disease and Other Dementias identifies six major areas that address the needs of individuals and families impacted by these diseases. The Work Group has also identified key partners necessary to assure success in achieving the goals outlined in this Plan. Collaboration and support from elected officials and state agencies will be critical to the Plan's success.

We acknowledge this Plan represents a "living document" that will evolve as our progress and further understanding of the disease also evolve. We invite you to read the Plan and consider how your contribution could help improve the lives of South Dakotans impacted by Alzheimer's/dementia today, and in the future.

—South Dakota Alzheimer's Disease and Other Dementias State Plan Work Group

STATE PLAN WORK GROUP

The following individuals contributed significantly to the creation and development of the South Dakota Alzheimer's and Other Dementias State Plan.

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SOUTH DAKOTA STATE PLAN TO ADDRESS
ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

TABLE OF CONTENTS

STATE PLAN OVERVIEW

Care for Alzheimer's disease and Other Dementias (AD) is not *what* it needs to be nor *everywhere* it needs to be in South Dakota for people with dementia (PWD) and their family caregivers. Through the recently conducted, comprehensive statewide needs assessment, it was determined that services and resources are inadequate or missing throughout the state. Where services and resources do exist, they are constrained by high costs, insufficient workforce numbers, a lack of dementia-specific training, and a debilitating and limiting stigma. Needs assessment participants did not see this as a reality unique to South Dakota, but as a struggle throughout the country.

These same participants were encouraged to learn that other states have taken the initiative to improve the care of PWD through state Alzheimer's plans. Participants believe creating a plan to meet the needs of South Dakotans connected to AD, while long overdue, is the right next step. They do not claim to have all the solutions but do share many common recommendations for improving the state of AD care in South Dakota based on the breadth and depth of their collective experience. They see the state plan as a road map and convener of influence, advocacy, and action.

The South Dakota AD State Plan Work Group cited participant stories, recommendations, and hope for the future to develop six vetted goal topics accompanied by recommendations and rationale. Their work resulted in actionable items that merge needs assessment data with tactical knowledge on how to accomplish the work in the most efficient and impactful way. The Work Group recognizes that developing the state plan is just the first step, but a transformative first step that has the potential to positively change thousands of lives across the state.

To assure the plan is implemented, monitored, measured, and sufficiently funded, the Work Group will work with state officials to establish the South Dakota Alzheimer's State Plan Task Force. This task force will be responsible for overseeing state plan implementation and update efforts and will serve as a liaison to stakeholders and partners. The State Plan does not presume to address all aspects of an issue as broad and complex as AD. As benchmarks are reached and the content evolves, the task force will be responsible for assuring the work does not become stagnant, and that progress toward improving the lives of those living with and amongst AD is continuously being sought, either through a revised plan, new plan, or continued monitoring of implemented actions.

Work has already begun to address the needs and build upon the assets that surfaced during the needs assessment. The most important measure to be taken in the next six months to assure the proposed work is accomplished, is to have the South Dakota legislature approve this state plan. Their approval will bring to light the critical needs of this underserved population.

PROCESS FOR PREPARING THE STATE PLAN

HISTORY:

South Dakota is one of four states without an AD state plan. Need for a state plan was identified in 2014 by a group of Alzheimer's advocates. State plans have typically been pursued in one of three ways: through grassroots efforts, as directive from the governor to the state agency, or through a legislative mandate.

When stakeholders met with Department of Health officials in 2014, it was determined that an AD state plan would best be founded through a grassroots effort with the establishment of a formal work group and guidance from the Alzheimer's Association's South Dakota Chapter.

Process objectives:

1. Formalize the South Dakota AD State Plan Work Group.
2. Conduct a statewide needs assessment.
3. Create a comprehensive needs assessment report to enlighten the development of a state plan.
4. Develop South Dakota's first state plan to address Alzheimer's Disease and Other Dementias.

OBJECTIVE 1: FORMALIZE THE SOUTH DAKOTA AD STATE PLAN WORK GROUP.

The South Dakota AD State Plan Work Group was established in 2015 with an Executive Committee and expanded to a larger group of stakeholders that began to formally convene in April 2017. The voluntary Work Group was comprised of 26 individuals determined to create a state plan that will work to meet needs, fill gaps in resources and services, and improve the overall quality of AD care in South Dakota for individuals living with the disease and their caregivers.

Criteria for work group selection included proximity to and experience with AD, degree of influence and/or expertise in the field, and commitment to seeing the work through. The Work Group met four times between April 2017 and February 2018. Members were tasked with contributing their experience with and perspective of AD, reviewing and approving methodology and materials, and ultimately engaging in state plan development under close guidance of the South Dakota AD needs assessment.

Work group members represent health care providers and administrators, advocacy organizations, state agencies, and family caregivers.

OBJECTIVE 2: CONDUCT A STATEWIDE NEEDS ASSESSMENT.

Comprehensive needs assessments are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans. The data gathered and presented is specifically related to AD in South Dakota, making for a focused data set to inform action and policy.

Planning:

During the planning phase, the Work Group set priorities and goals to assure the needs assessment would be a representative snapshot of AD in South Dakota. The Work Group sought to gather and present information that would bring about new findings, update existing ones, and confirm "what we know to be true." They were also interested in finding out what potential solutions would work best for South Dakota.

The following priorities and goals guided needs assessment development:

- Current availability, accessibility, affordability, and quality of services and resources.
- What availability, accessibility, affordability, and quality should look like.
- Gauge awareness of AD at all levels, including any stigma associated with AD.
- The adequacy of education and training available for anyone associate with AD.
- How AD is experienced by those living with it or working with it, and how that experience can be improved.

The Alzheimer's Association Needs Assessment Toolkit and existing AD state plans outside of South Dakota were also referenced during planning.

Methodology:

The needs assessment is based on a mixed-methods approach comprised of three key inputs:

1. Focus groups facilitated throughout South Dakota.
2. Online statewide needs assessment survey.
3. Secondary data collection and analysis.

Input 1 |Statewide focus groups

Focus groups sites were mapped out to be inclusive of both the urban and rural experience of South Dakota residents. The state's population of nearly 860,000 was divided into five regions based on its 35 legislative districts. Each region represented between six and eight districts and between 120,000 and 200,000 people. The regions were also constructed with points of common experience in mind, such as urban vs. rural and proximity to major health care institutions. Three focus groups were held in each region, totaling 15 focus groups in 13 cities and towns.

A purposive sample was sought by creating invitation materials—flyers, ads, and news releases— that explicitly stated what the focus groups aimed to do and who the ideal participant would be. A connection to AD, either personal or professional, was set as a condition of participation. An outreach strategy was created to ensure the invitations reached as many ideal participants as possible through established media resources and direct outreach by work group members. South Dakota legislators were invited via letter.

The 90-minute focus groups were held on weekdays either over the lunch hour or early evening to accommodate participant schedules. A light meal was offered to thank participants for their time. Registration was capped at 20 for each session.

Focus groups were purposed with collecting firsthand accounts of what AD looks like in South Dakota. A set of 12 questions was developed to gather the stories and emotions that would make for a compelling case for statewide attention and action. Participants were asked to identify their needs and barriers, share their definitions of support and quality, and share their recommendations for improving the care of someone living in South Dakota with AD. A total of **147** South Dakota residents attended a focus group.

Input 2 | Statewide needs assessment survey

An online statewide needs assessment survey was designed to a) complement the qualitative data of the focus groups; and b) reach a larger segment of the state's population. Sampling methods included purposive and convenience techniques. A purposive survey sample was sought by putting the survey in front of individuals with an established connection to AD either through the Alzheimer's Association's South Dakota Chapter or through the professional and personal networks of work group members. All focus group participants were encouraged to complete the survey. The survey was available via an online link or paper copy.

Convenience sampling took place through the circulation of paper surveys to places that those touched by AD might frequent, such as support groups, church groups, and rural health care clinics.

The 17-question survey included open-ended and closed-ended questions. Respondents were asked to identify the three most pressing needs of persons impacted by AD in South Dakota, rate the quality of AD care, and share their recommendations for improving care. In total, **1,025** South Dakota residents completed the needs assessment survey.

Input 3 | Secondary data collection and analysis

Secondary data provided an analysis of indicators for South Dakota, including population projections, social and economic factors, prevalence, health care workforce, and caregiving. An inventory of long-term care providers in South Dakota was included. Additional data sources were contributed to help frame the report. All data was housed in a database with the intent for it to be updated and used to support the state plan ongoing.

Special contribution:

Work group member James Barker, M.D. sought to include underserved populations in the study. He designed a questionnaire that involved five basic questions about AD and administered it verbally to 20 people at the Bishop Dudley Hospitality House. From their responses, he provided the following generalizations:

1. Most of them knew someone who had some form of AD.
2. No one had been a personal caregiver for anyone with AD, though they knew caregivers or had relatives who had been caregivers.
3. They did not know of the related problems in the caregiver's position.
4. They did not have suggestions for how state or local services could have made the situation better.

Dr. Barker concluded with acknowledging individuals without a place to sleep or roof over their heads are often not selected to be caregivers and are unlikely to think of organized system solutions that can help their friends or family.

With that said, he believes that the recommendations of the state plan will help these individuals and their family members who may now, or in the future, suffer from AD and need the coordinated and high quality of state services that will be advocated in the plan.

Limitations:

The distribution strategy for the statewide needs assessment survey was intended to reach as many individuals who have a connection with AD as possible. The sample relied heavily on the distribution channels made available by work group members. Less than 2% of the 1,025 survey respondents reported being Native American or American Indian while the U.S. Census estimates 9% of South Dakota's population was Native American in 2017. In an attempt to make findings more representative of the state's demographics, an additional survey was designed to gather data from South Dakota's American Indian population.

This survey was intended to gather information and perspective on needs relating to the experience and care of PWD in South Dakota who identify as American Indian, either in an urban or tribal setting. It was sent out to work group member networks, organizations who work with the American Indian population, and tribal representatives. While criteria for survey respondents was articulated, only 11 of the 71 survey respondents reported being Native American or American Indian. The 11 respondents were somewhat to not familiar with what is available for AD care in South Dakota and identified the availability of services and resources as a pressing need. These limited findings were not admissible into the study's findings.

After consulting with those well-versed in tribal community study inclusion, it was determined that the timeline did not allow for a revised inclusion strategy prior to state plan publication. A more formalized approach will be pursued at a later date, after which findings will be published and an action plan will be developed.

OBJECTIVE 3: CREATE A COMPREHENSIVE SUMMARY REPORT TO ENLIGHTEN THE DEVELOPMENT OF A STATE PLAN.

Maximizing Excellence, LLC (MELLC) developed survey and focus group content as well as accompanying distribution materials based on work group direction and feedback. MELLC conducted the statewide needs assessment survey and facilitated fifteen focus groups throughout the state. SLM Consulting, LLC collected and analyzed secondary data to support primary data findings. MELLC merged the three data sets to create a comprehensive statewide needs assessment report. The Work Group provided technical support throughout the process and were the recipients of the report.

OBJECTIVE 4: DEVELOP SOUTH DAKOTA'S FIRST STATE PLAN TO ADDRESS ALZHEIMER'S DISEASE AND OTHER DEMENTIAS.

Upon completion and review of the needs assessment report, the Work Group added five additional members to assist with the development of state plan content. These members were selected for their subject matter and policy expertise.

Six subcommittees were established to translate needs assessment findings into goals with supporting rationale and recommendations.

- Public Awareness.
- Access to Care.
- Family Caregivers.
- Training and Workforce Development.
- Safety and Legal Issues.
- Research and Data Collection.

All subcommittees created their own action plan, which were then reviewed by the full group for insertion in the state plan. The Work Group conducted a final review of the state plan document and granted approval for publication in December 2018.

STATEWIDE NEEDS ASSESSMENT: FINDINGS SUMMARY

1,172 South Dakota residents provided input on the state of AD care in South Dakota either by completing a survey or attending one of the fifteen focus groups held statewide. These individuals represent the full spectrum of how AD is experienced, from family caregivers to professional caregivers and from individuals living with the disease to those who have experienced firsthand the loss of a loved one to the disease. While each story was unique, there were five points of common experience and need. These points constitute the five key needs assessment findings that collectively detail a story of struggle and frustration experienced around AD care in South Dakota.

FIVE KEY NEEDS ASSESSMENT FINDINGS:

1. There is a need to increase the availability of quality services and resources to PWD and their caregivers in rural and urban settings.
2. AD services and resources need to be more affordable for facilities to provide and for families to access.
3. The current and projected South Dakota workforce needs to be adequately sized and skilled to meet the demand for care.
4. Professional care providers and family caregivers need education, training, and emotional support to improve care quality and administrative efficiencies.
5. South Dakota needs to reframe how AD is understood, perceived, and cared for throughout the state to reduce stigma and improve the quality of life a PWD experienced.

See pages 30-45 for an in-depth look at the five key findings from the needs assessment.

Participants provided the following advice to anyone and everyone responsible for seeing through what they identified as important and necessary for South Dakota.

- Make it a community effort. Incorporate and address the challenges of professions impacted by AD and then identify how they can all contribute.
- Mindset is important. Consider what you would like to see for your own family. What do you want available when AD comes to your home?
- Stay engaged and follow up with all the entities around the state because things can change quickly; (must be able to adapt).
- Read the statewide needs assessment study!
- Create an advisory committee that is assigned with manageable, incremental goals and held accountable to meaningful progress.

STATEWIDE NEEDS ASSESSMENT: IDENTIFIED REALITIES

AD SERVICES AND RESOURCES ARE INADEQUATE OR MISSING THROUGHOUT SOUTH DAKOTA.

- South Dakota's moratorium on nursing home beds does not allow nursing home facilities to consolidate or add more beds in sites that have already met their quota. The moratorium prohibits adding beds where they are most needed, limiting PWD options.
- Assisted living and nursing homes with *memory care* units exist, but not on the scale needed to meet growing demand. Many PWD have had to relocate to access memory care or settle with non-specialized care in their area.

> **Memory Care or Alzheimer's Special Care Unit (SCU):** SCUs are designed to meet the specific needs of individuals with Alzheimer's and other dementias. SCUs can take many forms and exist within various types of residential care. Including assisted living facilities, and they may or may not be locked or secure units. Such units most often cluster settings in which persons with dementia are grouped on a floor or a unit within a larger residential care facility.

- Limited services and resources exist to care for higher-acuity PWD. Behavioral health and crisis intervention is virtually nonexistent. The only option for many participants is the Human Services Center (HSC) in Yankton. Also, many long-term care facilities evict or do not accept these high-acuity PWD, leaving families with few options.
- Access to services and resources is significantly compromised for PWD in rural and small communities. Getting connected with primary care, specialty services, transportation, in-home care, care facilities, caregiver support, funding, and education was reported as difficult and discouraging.
- AD caregivers cannot find the respite care, support groups, education, training, and continuous guidance they need to navigate their journey with the disease to the best of their ability. This was reported as a barrier for family members trying to access the appropriate level of care to keep their loved one at home longer and maintain their quality of life. Caregivers consistently reported not knowing where to go or how to access care and support.
- Mandatory and/or standardized AD education and training is not in place for professional caregivers. Professional caregivers, and those that employ them, raised concern at their competency to meet the needs of patients and families. Family members shared many accounts of professional caregivers mishandling cases, attributing it in part to lack of dementia-specific training. They also shared that having trust in the ability, knowledge, and quality of their care providers is of great value (and concern) to them.
- Training and education is not prioritized amongst indirect care professionals, including financial and legal advisors, police, and emergency medical technicians (EMTs). Without this expertise in place, decisions are often not made in the best interest of the PWD and their family.

WHERE AD SERVICES AND RESOURCES EXIST, THEY ARE CONSTRAINED BY HIGH COSTS, INSUFFICIENT WORKFORCE NUMBERS, A LACK OF DEMENTIA-SPECIFIC TRAINING, AND DEBILITATING STIGMA.

- Memory care is more expensive for facilities to provide, and for a family to afford, than standard nursing care. Participants reported being forced to place their loved ones in long-term care facilities regardless of memory care needs due to affordability and a Medicaid reimbursement rate that works against having memory care as a viable option. Most memory care is private pay, which creates a financial barrier for many PWD. For some participants, their only viable option was to spend down their assets to qualify for Medicaid.
- Long-term care facilities that offer memory care are not required to accept Medicaid residents. Participants have found that these facilities typically limit the number of Medicaid patients they accept. The Medicaid reimbursement rate for long-term care facilities, especially small facilities, offers a low return for memory care and does not account for the heightened costs associated with providing memory care, including a lower staff to resident ratio, continuing education for staff, a non-mixed population, and increased security.
- PWD are often placed in settings that are ill-equipped for higher-needs/acuity residents due to personal reluctance to seek a diagnosis, delay of accurate diagnoses, and lack of knowledge on how to navigate services and resources for PWD. Assisted living facilities and home health agencies are often found too late in disease progression, prompting concern as to the quality of care such entities can provide to residents with dementia.
- There are not enough direct care workers for AD service and resource providers to adequately staff their operations. Difficulty in finding and retaining qualified staff—above and beyond quantity—compounds the issue. Participants think a shortage of health care professionals, and the noncompetitive pay scale of CNAs, are at the heart of the issue.
- The training and education that exists does not adequately prepare care providers. This includes the baseline of what AD is, to the more complex—handling behaviors, crisis response, medication management, and therapies. Participants see provider proficiency on these topics leading to better coordination amongst services, more consistent quality, and overall improvement in how AD is approached in health care.
- Participants reported that being a family caregiver often creates financial, emotional, and physical stress. 77% of survey respondents were somewhat or not familiar with available services and resources, and no primary point of access for information or referrals was identified. Access to adult day services and home health to ease such stressors are limited by few available options, and caps on the number of hours a caregiver can receive financial assistance to utilize the service. Caregiver support groups are hard to keep active in small communities.
- AD are met with significant stigma throughout South Dakota. It is not a topic people are comfortable talking about or seeing, and therefore participants have seen PWD pushed to the periphery of society. It was reported that stigma stops people from accessing care, seeking support, and discourages PWD and their caregivers from staying engaged in community life.

POINTS OF PROGRESS THAT HAVE BEEN RECOGNIZED:

- The value of memory care on a PWD’s quality of life is being more widely accepted and endorsed.
- Trained professional caregivers have increasingly demonstrated a person and family-centered care approach, treating PWD with dignity, spending one-on-one time with them, and incorporating personalized activities and family suggestions into care plans.
- Churches and faith circles have been reliable sources of support and community engagement.
- The Alzheimer’s Association’s South Dakota Chapter is the most visible advocate for PWD and their caregivers and is where participants reported going first for information.
- Participants rated the quality of AD care as good for hospice care, home health care services, adult day services, primary care involvement, non-physician health care professionals, auxiliary services, long-term care facilities, and community initiatives.

SOUTH DAKOTA AD STATE PLAN GOALS, RECOMMENDATIONS, AND RATIONALE

1. PUBLIC AWARENESS
   Highlight dementia as a **public health issue** and raise public awareness and understanding about Alzheimer's and other dementias throughout South Dakota. This includes educating the public and family and professional care providers about the importance of early detection and diagnosis, dementia risk factors and lifestyle interventions, and care resources available in the state.

2. ACCESS TO CARE
   Ensure that people living with dementia have access to affordable care in all areas of South Dakota including home and community-based services, residential care facilities, and end-of-life care settings.

3. FAMILY CAREGIVERS
   Empower and support family caregivers to help people with dementia live in familiar settings, cutting costs for families and for the state. Reduce caregiver stress by developing and expanding ongoing community resources and enhancing education and training to prepare family and volunteer caregivers. Promote the availability of caregiver education and support systems in all communities.

4. TRAINING AND WORKFORCE DEVELOPMENT
   Support the development of an adequately prepared and dementia-capable interprofessional workforce, including direct care workers, aides, site administrators, nurses, nurse practitioners, physician assistants, physicians, social workers, first responders, and other care providers. Dementia training standards should address the knowledge, skills, and attitudes necessary to meet the needs of people with dementia and their families in all care settings. Increase workforce capacity, particularly in underserved areas, to ensure that all parts of South Dakota are covered.

5. SAFETY AND LEGAL ISSUES
   Implement protocols to preserve the safety and legal rights of people with dementia, and the people closest to them.

6. RESEARCH AND DATA COLLECTION
   Establish data collection efforts that will increase the efficacy of service delivery to people with Alzheimer's or other dementias in South Dakota.

PUBLIC AWARENESS

GOAL STATEMENT:

Highlight dementia as a **public health issue** and raise public awareness and understanding about Alzheimer's and other dementias throughout South Dakota. This includes educating the public and family and professional care providers about the importance of early detection and diagnosis, dementia risk factors and lifestyle interventions, and care resources available in the state.

RECOMMENDATIONS:

A. Create a centralized online database of resources related to Alzheimer's and other dementias housed on the *Dakota at Home* website (dakotaathome.org), formerly known as the *ADRC*. Form a work group to ensure the information is up-to-date and culturally appropriate.

B. Develop a long-term media campaign educating South Dakotans about Alzheimer's and other dementias to reduce stigma and fear. The campaign should include information on the benefits of an accurate and early diagnosis, advance health care and financial planning, and resources available to those living with the disease and their caregivers. This should be spear-headed by the AD State Plan Task Force and accomplished through strategic public-private partnerships with the following:
    1. State legislators and state agency officials.
    2. Health care providers and organizations.
    3. Non-traditional partners such as bankers, financial planners, lawyers and other private-sector businesses, emergency first responders, and other professionals who have contact with individuals with dementia.
    4. The general public, including individuals at risk and youth.
    5. Individuals with dementia, their caregivers, and family members.
    6. Television and radio through earned media.

C. Coordinate culturally-appropriate public awareness campaign efforts with Native American communities, Tribal health agencies, and other underserved and minority population.

D. Adopt and publicize the 25 action items from the CDC's Healthy Brain Initiative 2018-2023 Road Map (released in October 2018) and the companion Road Map for Indian Country, which serves as a guide for public health officials. These action items promote brain health, improved care for people with cognitive impairment, and increased attention to caregivers.

E. Conduct a media campaign to educate the public about available care services, advance care directives, and end-of-life planning. Conduct a media campaign targeted towards health care professionals to educate them about additional dementia services available to their patients and about the CPT® Code 99483.

RATIONALE:

1. Respondents to the statewide needs assessment stated that stigma, matched with a lack of public awareness and support, can be detrimental to the person with dementia and family members.
2. Respondents expressed the need for a road map to help them navigate the disease.
3. Public awareness campaigns provide factual information about Alzheimer's and highlight lifestyle interventions that can reduce the risk of developing the disease.
4. Early diagnosis offers personal benefits to individuals and caregivers and also decreases costs.
5. Dementia is a public health issue because the burden is large, the impact is major, and there are ways that public health can intervene. Shining a light on Alzheimer's and other dementias and educating the public about them will inevitably reduce stigma.
6. Creating a centralized database for information will also ease the burden for South Dakota families impacted by this disease.

ACCESS TO CARE

GOAL STATEMENT:

Ensure that people living with dementia have access to affordable care in all areas of South Dakota including home and community-based services, residential care facilities, and end-of-life care settings.

RECOMMENDATIONS:

A. Partner with the state legislature to relieve the financial burden of care for families. Consider policies such as a caregiver stipend, tax credits, and grants used to fund care performed in the home and community.

B. Form strategic partnerships with public and private organizations to bring care services to low-access areas of South Dakota. Capacity-focused workforce development policies could be tailored to incentivize new healthcare professionals to practice in underserved regions.

C. Increase Medicaid reimbursement rates for long-term care facilities offering specialized memory services and community-based services, such as adult day centers, provided to people living with dementia and their families.

D. Enact policies that enhance dementia-friendliness and provide specialized memory care in long-term care facilities.

E. Readdress the moratorium on nursing home beds in South Dakota.

F. Support policies that expand and fund telehealth capacity in underserved and rural areas.

G. Consult with representatives from Native American reservations to learn how to best meet the needs of their populations and enact the needed services. Additional guidance is available in the CDC's Healthy Brain Initiative Road Map for Indian Country.

RATIONALE:

1. The financial and emotional costs of caring for people living with Alzheimer's or another dementia are often unduly burdensome for families. Many family caregivers must take time off from work or stop working altogether to provide care for their loved one. In some cases, residential care can be cost prohibitive.

2. People with dementia, according to needs assessment participants, feel most comfortable in a familiar, homelike setting.

3. Geographic regions, including Native American reservations, exist within South Dakota without access to certain care services.

FAMILY CAREGIVERS

GOAL STATEMENT:

Empower and support family caregivers to help people with dementia live in familiar settings, cutting costs for families and for the state. Reduce caregiver stress by developing and expanding ongoing community resources and enhancing education and training to prepare family and volunteer caregivers. Promote the availability of caregiver education and support systems in all communities.

RECOMMENDATIONS:

A. Provide education, training, and easily accessible information to family caregivers. Training should include printed materials, support groups, web-based resources and webinars, and in-person education sessions.

B. Enact policies that reduce the emotional burden on family caregivers, such as grants for partially reimbursing the cost of respite care and other home and community-based services.

C. Enlist and educate faith-based communities as resources that can help support families living with dementia. Invite faith leaders and parish nurses to applicable training opportunities and request their assistance in disseminating information and materials.

D. Work to develop dementia-friendly public spaces, possibly in coordination with community-based services such as adult day centers.

E. Establish a volunteer structure to provide companionship and help with activities of daily living and instrumental activities of daily living.

RATIONALE:

1. Family caregivers require comprehensive and continuous community-based services. Caregivers report needing quality care for their loved ones with dementia, emotional support, care coordination, and a sense of preparedness for disease progression. Nearly half of respondents to the needs assessment identified the need for education and training for caregivers and for ongoing guidance that is responsive to individuals, reporting that caregivers cannot find the respite care, support groups, education, training, and continuous guidance they require.

2. Community-based support groups are the most effective way to meet family caregivers' ongoing needs. These groups are hard to keep active in small communities and require ongoing structure and training, as well as a dynamic membership. In addition to family caregivers, support group members would include former caregivers, friends and family of caregivers, health and medical personnel, faith-based community leaders, and concerned volunteers.

TRAINING AND WORKFORCE DEVELOPMENT

GOAL STATEMENT:

Support the development of an adequately prepared and dementia-capable interprofessional workforce, including direct care workers, aides, site administrators, nurses, nurse practitioners, physician assistants, physicians, social workers, first responders, and other care providers. Dementia training standards should address the knowledge, skills, and attitudes necessary to meet the needs of people with dementia and their families in all care settings. Increase workforce capacity, particularly in underserved areas, to ensure that all parts of South Dakota are covered.

RECOMMENDATIONS:

A. Advocate and support the inclusion of information on Alzheimer's and other dementias in the training curriculum and continuing education requirements of physicians, nurses, and other allied direct care professionals to ensure the implementation of competency-based dementia training standards. Curriculum development should include comprehensive information regarding early detection and diagnosis of cognitive impairment, dementia care interventions, management of dementia, person-centered care, end-of-life planning, and best practices for communicating with people with dementia and their loved ones.

B. Assess the distance learning capacity in the state as a means to provide competency-based, dementia-specific education and training for individuals providing direct care services to people with dementia (i.e. adult day services, non-medical home care, home health care, assisted living, skilled nursing, memory care units, hospital), including family caregivers. Create an electronic system of verifying and tracking training progress.

C. Create and promote opportunities that encourage students and young adults to engage in work or volunteer experience with people with dementia to increase interest in careers in geriatrics/gerontology. One strategy is partnering with educational institutions and large service providers to highlight the benefits of a strong healthcare workforce and facilitate discussions about career mobility in the dementia sphere of healthcare.

D. Develop standardized training for professionals who provide indirect care to those with dementia, including, but not limited to, financial and legal advisors, law enforcement, emergency medical technicians, and fire fighters.

E. Incentivize advanced education for health care providers, especially in underserved areas, who specialize in geriatrics and dementia care, such as loan forgiveness or repayment options, stipends, scholarships, and relocation expenses.

RATIONALE:

1. Needs assessment participants believe that health care professionals at all levels of care are often unprepared to address dementia. The survey revealed numerous occasions where people with dementia and/or family members were frustrated by delayed diagnosis or misdiagnosis, and sensed discomfort on the part of health care professionals in providing patient education and disease management information. Efforts to enhance the knowledge and skills and alter unhelpful attitudes of practicing health care professionals have the most immediate impact upon provision of care for people with dementia and their families.

2. Support distance learning opportunities to overcome time and travel barriers to accessing dementia-specific training.

3. Workforce shortages currently exist. The shortage of available, trained workers will continue to increase with the aging of the Baby Boomer cohort. Long-term workforce development is essential. The increasing prevalence of dementia will impact the state's ability to meet workforce needs.

4. Without appropriate training, indirect care providers make decisions that, according to needs assessment participants are not in the best interest of people with dementia or their families.

5. Service providers may not have the requisite knowledge to appropriately care for those with dementia, lowering quality of care and of life for those patients.

SAFETY AND LEGAL ISSUES

GOAL STATEMENT:

Implement protocols to preserve the safety and legal rights of people with dementia, and the people closest to them.

RECOMMENDATIONS:

A. Provide educational resources in the form of safety tips and best practices to help family and friends protect people with dementia in their homes.

B. Create a flowchart or other tool to help people with dementia and their families through the process of assessing the ability to drive an automobile.

C. Actively promote awareness among first responders, employers, and the community to better recognize people with dementia and promote the use of evidence-based techniques to improve communication and interaction, including alternatives to physical restraints for first responders.

D. Establish a standard operating procedure for physicians and clinicians to engage with family caregivers through all stages of dementia.

E. Work with lawmakers and first responders to implement a “Silver Alert” when a person has wandered, both as a pedestrian and a driver, establishing dementia-specific criteria.

F. Implement laws that adopt uniform procedures and support legal documents protecting the beliefs, desires, and assets of people with dementia. These documents may include: Medical Orders for Scope of Treatment (MOST), Health Care Directives, Living Wills, Power of Attorney (POA) and/or guardianship.

G. Establish a POA registry to protect people with dementia and lessen the burden for those holding legitimate legal authority.

H. Support legal measures to further acknowledge, identify, and prevent abuse, neglect, and exploitation of people with dementia.

RATIONALE:

People living with Alzheimer’s and other dementias have an increased risk of wandering, abuse, neglect, and exploitation, including financial exploitation. Educating families, care facilities, and first responders, helps reduce the risk associated with these issues.

RESEARCH AND DATA COLLECTION

GOAL STATEMENT:

Establish data collection efforts that will increase the efficacy of service delivery to people with Alzheimer's or other dementias in South Dakota.

RECOMMENDATIONS:

A. In order to accurately assess the number of South Dakotans who are currently experiencing subjective cognitive decline, Alzheimer's, or another dementia and identify trends among these individuals, the South Dakota Department of Health should establish a dementia registry.

B. Regularly include questions about cognitive health in South Dakota's annual Behavioral Risk Fact Surveillance System (BRFSS) survey.

C. In conjunction and coordination with the South Dakota State Medical Association (SDSMA) and the South Dakota Department of Health (SDDOH), amend death certificate completion to include information regarding diagnoses of dementia.

D. In conjunction with the SDSMA, disperse information regarding current national registries which may include an Alzheimer's prevention registry, Alzheimer's gene Match registry, the brain health registry, and Alzheimer's prevention trials web study.

E. In conjunction with currently established research programs within the state of South Dakota, encourage local involvement in national clinical trials whose focus includes research into causation, diagnosis, prevention, and treatment of Alzheimer's and other dementias.

F. Promote access to the Alzheimer's Association's Trial Match clinical trial program.

G. Encourage a public/private partnership that helps to increase dementia-specific research funding.

H. In conjunction with the SDSMA, conduct at least an annual review of current research findings that has been peer reviewed for general acceptance and could be incorporated into existing workforce training programs.

RATIONALE:

1. Public health efforts in South Dakota can be enhanced through more thorough data collection. Collection can be performed in several ways, including the BRFSS survey and a dementia registry modeled on existing disease or dementia registries.

2. The primary cause of death in patients with Alzheimer’s or another dementia is typically another condition. Reporting dementia on death certificates in addition to primary cause of death enhances understanding of mortality, co-occurring chronic conditions, and risk factors related to dementia.
3. The current federal Omnibus budget recently passed and signed into law includes an additional $414 million to a total of $1.8 billion for research for Alzheimer’s and other dementias through the National Institutes of Health (NIH) which is a larger increase this year than was received by the National Cancer Institute. South Dakota has several established clinical research departments within the state that should be encouraged to apply for research grants or to become a secondary site for clinical trials involving those with Alzheimer’s and other dementias.
4. Despite the federal government’s encouraging position on the importance of funding clinical research into various aspects related to Alzheimer’s and other dementias, it is prudent to encourage all willing partners to become involved in the research efforts.

KEY PARTNERS FOR SUCCESS

AARP South Dakota

Adult Day Service Providers

Alzheimer's Association's South Dakota Chapter

Area Agencies on Aging

Assisted Living Association of South Dakota

Assisted Living Facilities

Attorney General's Office

Avera Health

Avera Research

Behavioral Health Care Providers

CAREgivers by Active Generations

Churches and Faith-Based Communities

Dakota at Home

Department of Motor Vehicles (DMV)

Financial Industry Regulatory Authority (FINRA)

First Responders

Great Plains Quality Innovation Network.

Health Care Trade Associations

Home Health Care Providers

Hospital Systems

Long-Term Care Facilities

National Family Caregiver Support Program

North Central Society for Post-Acute and Long-Term Care Medicine

Physicians & Clinicians

Regional Health

Religious Institutions

Respite Care Providers

Sanford Health

Sanford Research

South Dakota AD State Plan Task Force

South Dakota Association of Health Care Organizations (SDAHO)

South Dakota Bankers Association

South Dakota Bar Association

South Dakota Department of Health (SDDOH)

South Dakota Department of Human Services (SDDHS)

South Dakota Division of Long-Term Services and Supports (SDLTSS)

South Dakota Foundation for Medical Care

South Dakota Health Care Association (SDHCA)

South Dakota Medical Association (SDSMA)

South Dakota Ombudsman

State Legislators

Tribal health leaders

University of South Dakota Sanford School of Medicine—Geriatrics Fellowship Program

Veterans Administration (VA)

APPENDICES

RATIONALE FOR A SOUTH DAKOTA AD PLAN

78.4% of needs assessment survey respondents reported being concerned to very concerned about how AD could affect themselves or their loved ones someday.

This concern is driven in part by being closer to, or more aware of, the impact of AD than the average South Dakotan. 76.4% of respondents shared a primary connection of either being a son, daughter, or other family member of a person with dementia (PWD) or having worked with PWD in a professional capacity. Nearly 65% identified as a family member, friend, or professional caregiver to a PWD.

Personal concern was scaled to statewide concern when focus group participants defined the need for a state plan based on 1) increasing prevalence of AD in South Dakota and 2) increasing aging population in South Dakota.

1. INCREASING PREVALENCE OF AD IN SOUTH DAKOTA

As one participant said, *"Everyone is going to be touched by AD in some way."* Participants foresee an increase in the amount of AD cases diagnosed annually and with that, an increase in the number of people accessing care. Given their perception that AD care is already inadequate with the state's current rate of diagnosis, participants believe that to get ahead of the issue and assure care is available for all of those who will come to need it, AD needs to be addressed at the state level.

- 18,000 South Dakota adults, age 65 or older, are projected to have Alzheimer's Disease in 2020, with a projected number of 20,000 adults to be diagnosed by 2025; resulting in a 17.6% increase in prevalence from 2020 to 2025 *(Alzheimer's Disease Facts and Figures Report, 2018).*
- Alzheimer's Disease was the fifth leading cause of death among South Dakota adults from 2011-2015. It was the third leading cause of death in adults aged 80-89 and the second leading cause of death in adults aged 90 and over (*South Dakota Department of health, Office of Health Statistics, 2015).*

2. INCREASING AGING POPULATION IN SOUTH DAKOTA.

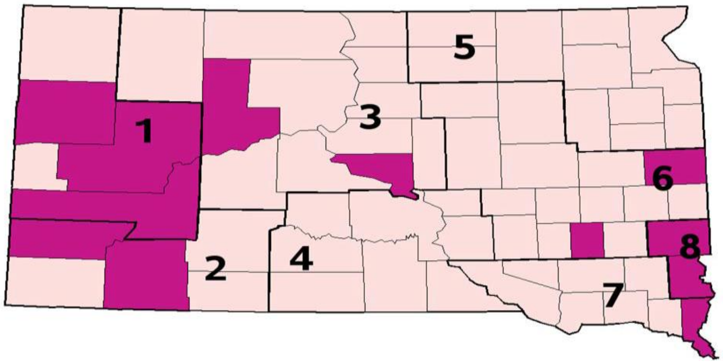
Participants see South Dakota's aging population increasing every day as Baby Boomers age. They believe South Dakota's Baby Boomer population—born between 1946 and 1964—will only increase in coming years with an increase in transplant retirees attracted to South Dakota as a "best place to retire." As more South Dakotans live longer, participants recognize their health care needs will increase. With an increase in the prevalence of AD and an increase in the majority age demographic (65+) most likely to be diagnosed with AD, a state plan on AD is deemed necessary to *"take care of our own."*

- The South Dakota population 45 years of age and older is projected to increase from 356,306 in 2015 to 435,595 in 2035. Those 65 years of age and older are projected to increase from 139,749 in 2015 to 227,225 in 2035 (*Department of Sociology and Rural Studies, SDSU, 2012).*
- Life expectancy in South Dakota is 82 years of age for females and 77.2 for males. From 1990 to 2016 the population 85 years and older has increased by approximately 7,000 persons *(Institute for Health Metrics and Evaluation, 2016)*.

RATIONALE: SNAPSHOT OF AD NOW AND FUTURE IN SOUTH DAKOTA

SOUTH DAKOTA'S ELDERLY POPULATION PROJECTION

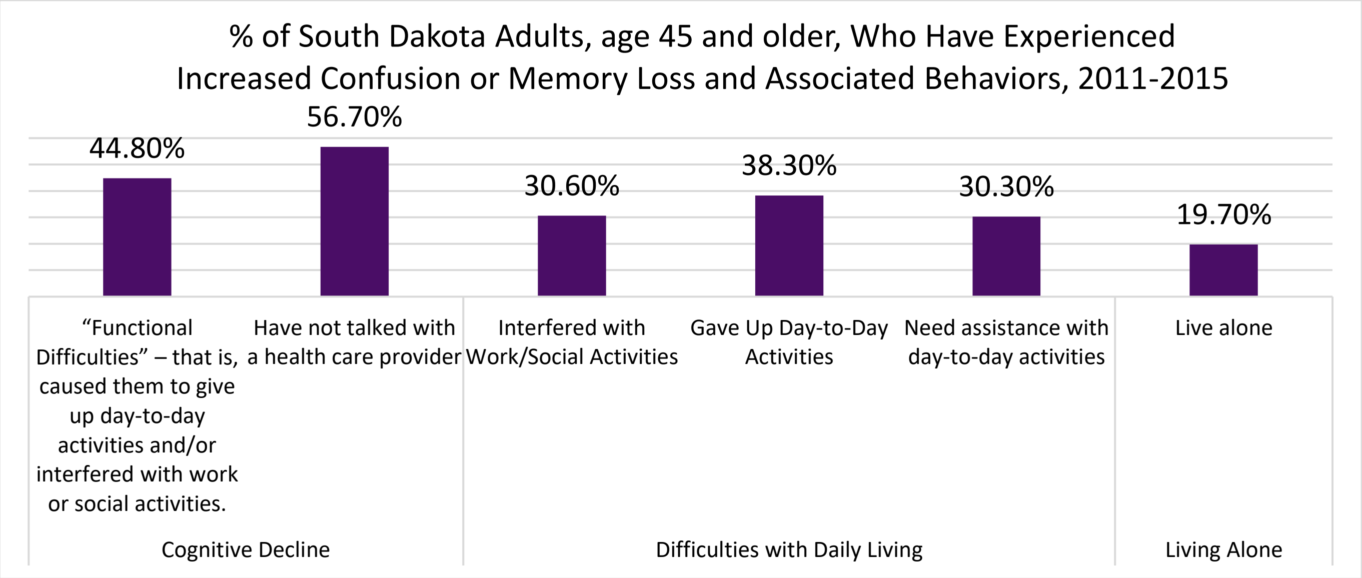
South Dakota counties where the elderly disabled population is expected to double from 2010 to 2035: Brookings, Butte, Custer, Hanson, Hughes, Lincoln, Meade, Minnehaha, Oglala Lakota, Pennington, Union, and Ziebach.



Abt Associates' analysis of South Dakota Data Center's Population Projections data.

CONFUSION AND MEMORY LOSS IN SOUTH DAKOTA

- 13% of South Dakota adults in hospice had a primary diagnosis of Dementia in 2018. *(Alzheimer's Disease Facts and Figures Report, 2018)*
- 6.3% of adults 65 years or older, reported increased confusion or memory loss that is happening more often or is getting worse in the preceding 12 months.39.1% of older adults 65 years or older, who have experienced increased or memory loss who reported their confusion or memory loss interferes with their ability to engage in social activities or household chores. *(BRFSS, 2015, Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. Healthy Aging Data)*



RATIONALE: SNAPSHOT OF AD IN SOUTH DAKOTA VIA THE NEEDS ASSESSMENT SURVEY

SATISFACTION WITH AD SERVICES AND RESOURCES

Scale of 1-5, 5 being very satisfied

919 of the survey respondents rated their satisfaction with the following AD services and resources in South Dakota.

2.9	Information about and guidance in finding services and resources upon and beyond diagnosis
2.9	Quality of services and resources
2.8	Education and training of health care professionals and caregivers
2.7	Services and resource available in your area
2.7	Public awareness
2.6	Community support for family and non-family caregivers of persons with AD
2.3	Coverage of costs of services and resources

QUALITY OF AD CARE

Scale of 1-5, 5 being excellent

913 of the survey respondents rated the quality of AD care in South Dakota.

4.3	Hospice care
3.9	Home health care services
3.9	Adult day services
3.7	Non-physician health care professional
3.6	Auxiliary services (drug treatment, behavioral health, etc.)
3.6	Assisted/long-term care facilities
3.6	Primary care/family doctor involvement
3.5	Community based initiatives (transportation, public service preparedness, etc.)

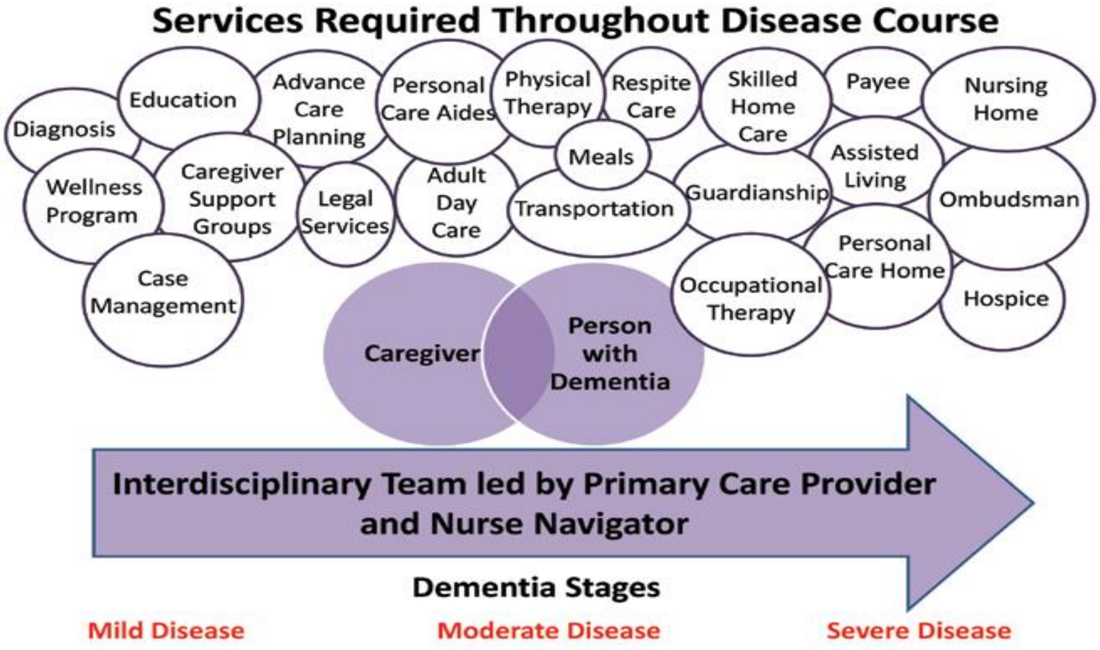
MOST PRESSING NEEDS

932 of the survey respondents weighed in on what the three most pressing needs for persons in South Dakota impacted by AD.

1	Coverage of costs for services and resources	55.7%
2	Information about and guidance in finding services and resources upon and beyond diagnosis	55.0%
3	Services and resources available in your area	52.9%
4	Education and training of health care professionals and caregivers	43.2%
5	Quality of services and resources	40.5%
6	Community support for family and non-family caregivers of PWD	36.7%
7	Public awareness of the disease	10.9%

VISION FOR AD CARE

Needs assessment participants painted a broad picture of all the services and resources involved in a PWD's and their caregiver's experience across three present but hard to discern stages of dementia. An interdisciplinary team leading both parties through a continuum of care was desired and seen as best practice. As it stands in South Dakota, many of the services displayed are uncoordinated, inconsistent in quality, and lack proper funding.



Adopted from Montana's Alzheimer's and Dementia State Plan, 2016.

AN IN-DEPTH LOOK AT THE FIVE KEY FINDINGS

1. THERE IS A NEED TO INCREASE THE AVAILABILITY OF QUALITY SERVICES AND RESOURCES TO PWD AND THEIR CAREGIVERS IN RURAL AND URBAN SETTINGS.

RURAL AND URBAN SETTINGS

57% of the population in South Dakota live in urban areas, while 43% of the state's population lives in rural areas. The majority of South Dakota's 66 counties are designated as rural or frontier. *(Decennial Census 2010, South Dakota)*

Participants spoke often of the rural-urban divide and the disparity in services and resources between the two was articulated when participants were asked to list what is available and missing in their community for AD care. The divide was identified as a source of difficulty for the state plan to address due to how similar the needs of the two populations are but how different service and resource delivery looks like for each.

SERVICES AND RESOURCES = COMPREHENSIVE CARE

Improving the care of PWD in South Dakota requires that all residents have access to a comprehensive suite of services and resources, ideally presented within a continuum of care framework. Participants are not satisfied with the services and resources available to them in their area.

The following reflects how participants define comprehensive care for a PWD:

- Long-term care:
  - Assisted living, preferably with memory care.
  - Skilled nursing, preferably with memory care.
  - Hospice.
  - Home health care.
  - Home care.
- Health care supports and auxiliary services:
  - Care providers: primary care, mental and behavioral health, geriatricians, etc.
  - Access to AD expertise for diagnosis, treatment, and navigation.
- Caregiver supports:
  - Alzheimer's Association.
  - Respite care.
  - Ombudsman advocate.
  - Support groups for PWD and caregivers.
  - Adult day services.
- Community supports:
  - AD-friendly public spaces.
  - AD-aware representatives from professions that work with PWD and their families, including emergency, financial, legal, and retail services.

> *"It should be a priority to have the right care available to the right person at the right time."*

LONG-TERM CARE IN SOUTH DAKOTA

According to AARP's 2017 Long-Term Services and Supports Scorecard, South Dakota needs to improve its long-term care options for residents. The national scorecard measures the care available in states based on accessibility, choice, and quality. It also assesses their support for family caregivers and the transitions between health facilities and home. South Dakota ranks 32nd overall. The state ranks lowest in the categories of effective transitions and choice of setting for care.

Needs assessment participants rated the quality of long-term care facilities a 3.6, on a scale of 1-5, with 5 being excellent. Quality could be improved with increased consistency and quality assurance among care providers and facilities, and facilities that are designed to respond to the unique needs of PWD.

For many, quality of care is second to what is available. When memory care in a long-term care facility is not an option, participants reported having to place PWD in general population facilities, which are not designed with AD symptoms in mind. Participants also spoke of difficulty in transitioning between care settings. Without a continuum of care guiding these transitions and a lack of direction from providers, participants reported PWD staying longer than they should in assisted living facilities and not being able to find nursing facilities with open memory care beds or general population beds close to home when the time comes. Home health was not a common option amongst participants and was not a top recommendation given by physicians when discussing care plans with caregivers.

As stated by the South Dakota Department of Health, the levels of institutional care in South Dakota include nursing facilities, assisted living centers, adult foster care homes, residential living centers, congregate housing, and home health services.

Assisted living facilities	171
Skilled nursing facilities	109
Home health agencies	43
Residential living centers	36
Hospice options	25
Adult foster care homes	15
Congregate housing	X

Department of Health Provider List, 2017.

Nationally, ADRD is most prevalent among nursing home residents (50.4%). 44.7% of hospice residents, 39.6% of residential living centers, and 31.4% of home health have a diagnosis of ADRD. It is least prevalent among adult day services center participants (29.9%). Over 75% of long-term care facilities do not solely serve PWD or offer an ADRD unit.

CDC/NCHS, National Study of Long Term Care Providers, 2014)

South Dakota ranked 16th for available assisted living beds in 2010, at 3.4 available beds per 100 elderly individuals. The state continues to have the 2nd fewest Medicare skilled home-health episodes, with just over 5 episodes per 100 elderly individuals.

Existing state long-term care capacity was judged insufficient to meet the coming demand, with nursing homes needing to be replaced and rebalanced, and assisted-living capacity, home health care services, and home and community-based services (HCBS) additionally requiring expansion.
ABT Associates Evaluating Long-Term Care Options for South Dakota, Update 2015.

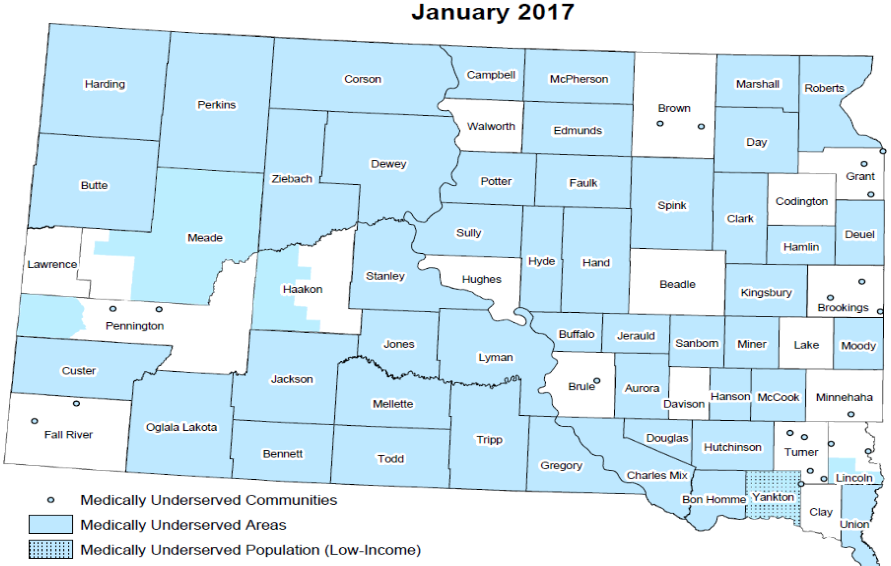
HEALTH CARE SUPPORTS AND AUXILIARY SERVICES

Participants rated the quality of primary care physicians, non-physician health care professionals, and auxiliary services as good. However, they rated their satisfaction with services and resources available in their area as less than satisfactory and identified having more services and resources available as a pressing need for South Dakota.

Disparity in access to health professionals and medical services exists. Shortages are geography and income based.

- Across South Dakota's 66 counties, there are 47 medically underserved areas.
- 24.4% of the state's population lives in a health professional shortage area.
- As of January 2017, South Dakota has 200 health professional shortage areas—87 primary care and 49 mental health. The rate of primary care physicians per 100,000 population is 85.3; it is 183 for mental health providers.

SOUTH DAKOTA MEDICALLY UNDERSERVED AREAS/POPULATIONS
January 2017



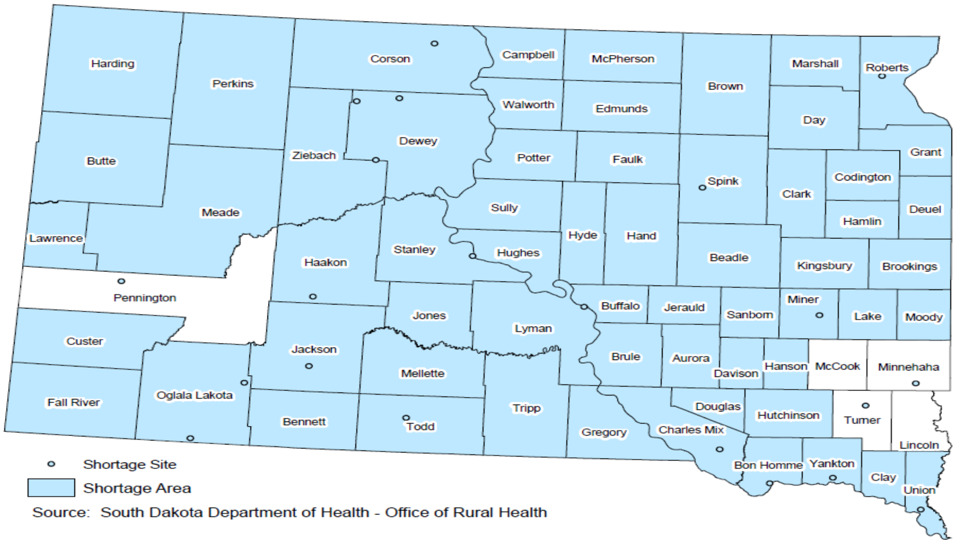
Source: South Dakota Department of Health - Office of Rural Health

Participants report that limited access to health professionals and medical services negatively affect the quality of life a PWD and their caregiver experiences.

Participants living in underserved and shortage areas reported having to travel more than one hour and up to three for initial and follow-up appointments. This frequency of travel is difficult to schedule for family caregivers who maintain employment and can agitate a PWD, as they thrive with consistency in settings. Even when placed in a residential setting, PWD are not guaranteed access to physicians or needed specialists because they often do not provide in-person or telemedicine consultation to facilities, resulting in required travel.

It is hard to find the right doctor to diagnose AD in South Dakota. Long wait times to see physicians who are generally not well versed in the different types of dementia typically leads to a string of referrals, delaying proper diagnosis far past onset and acknowledgement of symptoms.

SOUTH DAKOTA HEALTH PROFESSIONAL SHORTAGE AREAS
MENTAL HEALTHCARE
January 2017

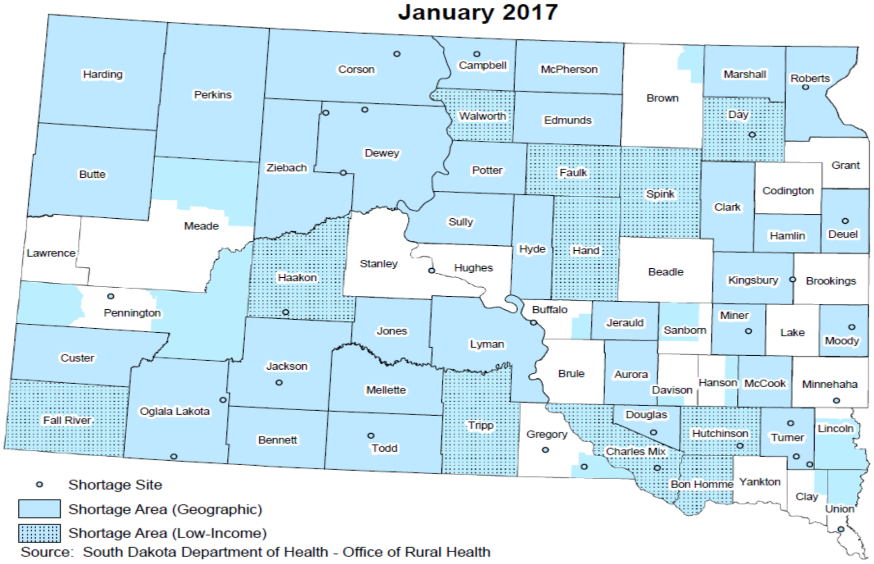


Source: South Dakota Department of Health - Office of Rural Health

Participants do not think PWD are provided the mental health care they need. Their loved ones have been admitted to the Human Services Center because the mental health care available in the community or in a residential facility was either nonexistent or ill equipped to manage the behavioral health issues of AD.

Undiagnosed PWD have been sent to jail because first responders do not know how to identify the behavioral symptoms of AD. Treatment with medication can take away what was left of their family member's personality. Participants see maltreatment of PWD directly linked to a lack of mental health care and an overall lack of proper crisis management—not having Plan B.

SOUTH DAKOTA HEALTH PROFESSIONAL SHORTAGE AREAS
PRIMARY MEDICAL CARE
January 2017



Source: South Dakota Department of Health - Office of Rural Health

Many participants have entrusted the care of PWD to non-AD physicians.

They have found it difficult to find and access AD experts or elder care experts, such as geriatricians.

CAREGIVER SUPPORTS

Nearly 65% of needs assessment participants—survey and focus groups—identified with being a family or professional caregiver for a PWD. Caregivers see themselves as primarily responsible for the wellbeing of PWD, more heavily involved in daily care than physicians, and carrying the voice of their loved ones and patients forward. Research supports this perception by asserting that family caregivers will provide the majority of hands-on care to PWD and that there is no practical alternative to the family caregiving workforce.

What family caregiving looks like in South Dakota…

- There are 43 million hours of unpaid care in South Dakota. Unpaid care in South Dakota is valued at $4,385 (millions). *(Alzheimer's Facts & Figures Report, 2017)*
- Caregivers in South Dakota have higher health care costs at $27 million. *(Alzheimer's Facts & Figures Report, 2017)*
- In 2015, $770,572 was expended for caregiver's respite care in South Dakota. *(Administration for Community Living, 2017)*
- 1 out of 5 needs assessment survey respondents indicated that their full-time employment status has been influenced by their caregiver status.

Participants suggested that what is beneficial for a PWD is beneficial for a caregiver, and vice versa, because they are so intrinsically tied to—and dependent upon—each other's health and quality of life. Caregiver support was defined as quality care, emotional support, community awareness, care coordination, accessibility, preparedness for disease progression, and crisis-management plans. Participants stated access to caregiver supports like adult day services and support groups can ease caregiver stress and provide cost-savings to families by keeping PWD independent and in their homes longer. They defined access to caregiver supports as knowing what is available in their community, how to get connected with those supports, and having flexible availability.

What participants said about the benefits of caregiver supports…

Adult Day Services

- Caregiving is very taxing—mentally and physically—without this service.
- Assist those that are trying to keep people at home longer.
- Gives a break to caregivers and facilities.

Support groups

- Opportunity for caregivers to not feel so alone and stay engaged.
- Share best practice helps people understand the stages of the disease the person is going through.

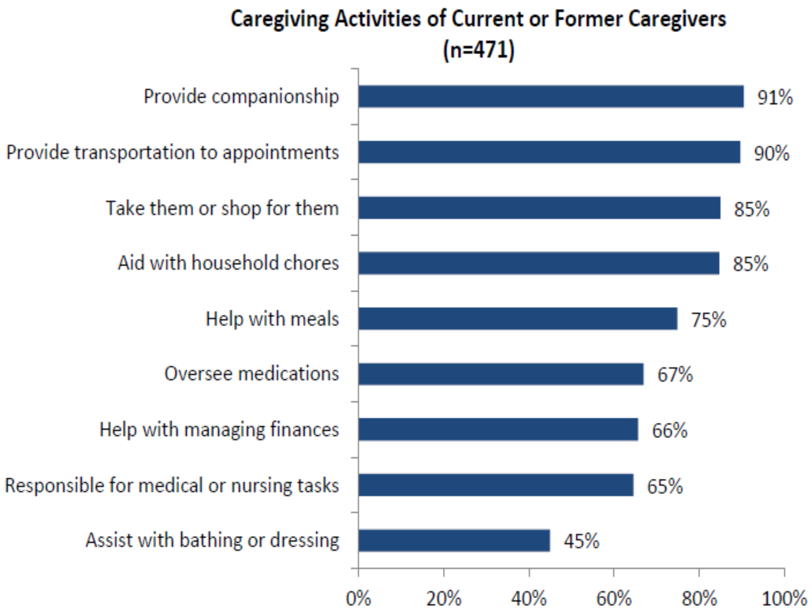
Adult Day Services and support groups are typically accessed through long-term care facilities and senior centers in South Dakota. It was reported that support groups are difficult to keep active in small communities. The state's LTSS program is seen as a valuable program for administration of caregiver support but riddled with limitations on service area and use.

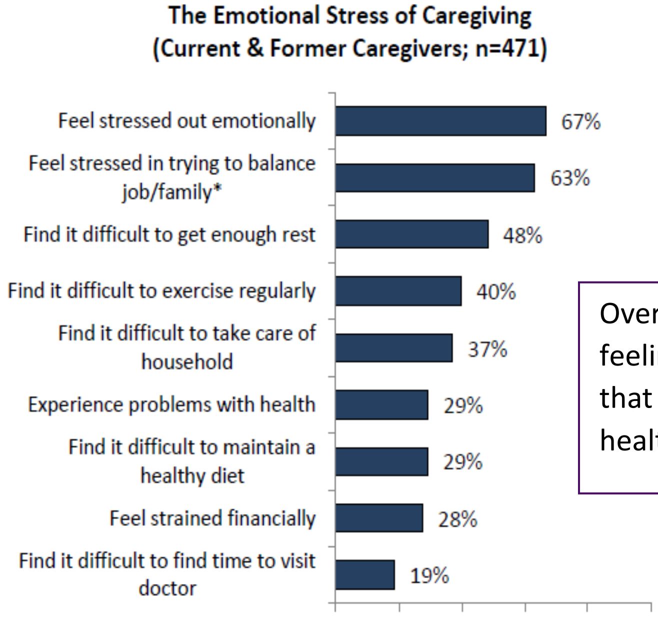
Other caregiver supports that surfaced included financial and legal preparation and planning, education and training, and the Alzheimer's Association's South Dakota Chapter.

WHAT FAMILY CAREGIVING LOOKS LIKE IN SOUTH DAKOTA (NONSPECIFIC TO AD)

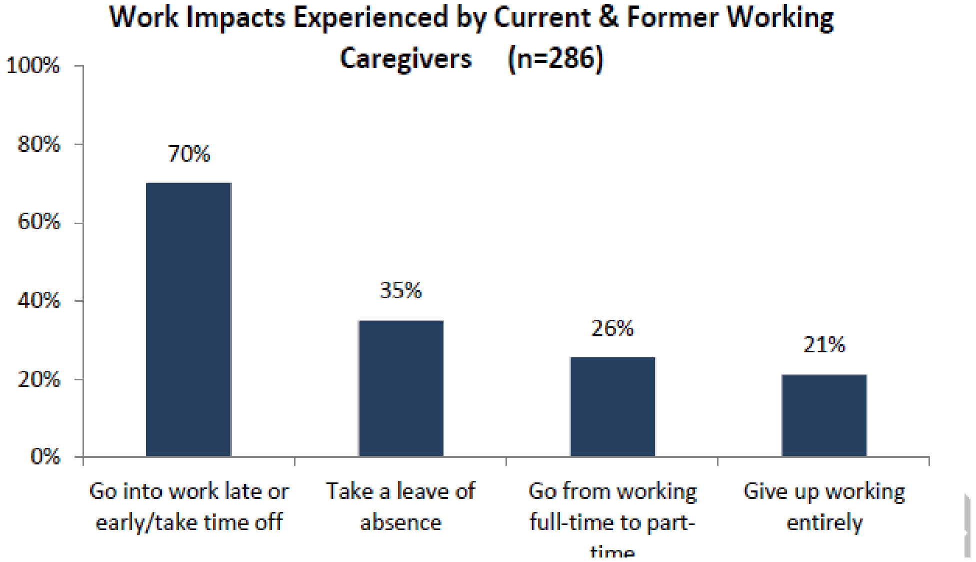
Findings from the AARP South Dakota Caregivers Survey, 2017

Two in three caregivers reported oversight in medications or responsibility for medical or nursing tasks.





Over 8 in 10 caregivers (82%) reported feeling at least one of the nine stressors that affect their health behaviors, overall health, and financial wellness.



78% of working caregivers have taken at least one of these four actions impacting their work while providing care.

COMMUNITY SUPPORTS

Participants defined adequate community support with the following statements:

- Adequate services and resources in the community for PWD and caregivers.
- Efforts to do away with the stigma associated with AD.
- Knowledge, resources, and support needed are visibly present, and referrals to community supports are made.

Participants reported being unsatisfied with the community support available for caregivers of PWD. They believe the quality of community-based initiatives—such as transportation to access health care services and public preparedness to proactively meet the needs of PWD—could be improved upon.

Much of the community support participants have experienced has been through friends and family, and close-knit community groups that the PWD was involved in prior to being diagnosed.

Community support reported to be already present in some South Dakota communities:

- Ability to take community outings to places that welcome PWD with amenities like family restrooms.
- Parish nurses help keep PWD in the home.
- Exposure to community life is dependent upon the family's willingness to take the patient out. Facilities are limited in their capacity to do so.
- Facilities that support continued engagement in an individual's likes, such as gardening.
- Families come out and support local AD efforts.
- Church groups and coffee groups that welcome their friends with AD.
- The ministerial associations are supportive emotionally and spiritually.
- Meals on Wheels keep AD patients living at home engaged.
- Some non-medical home care providers will take patients out and about.
- Some facilities try to bring as much community life into the walls, like inviting local schools to perform.

2. AD SERVICES AND RESOURCES NEED TO BE MORE AFFORDABLE FOR FACILITIES TO PROVIDE AND FOR FAMILIES TO ACCESS.

Coverage of costs for services and resources was identified as the most pressing need for persons in South Dakota impacted by AD. An AD diagnosis affects costs for both facilities and individuals.

For the PWD and their family, the list of costs was described as "overwhelming." They include primary physician and specialist visits, diagnostic tests, respite care, home health care, long-term facility care, medications, lost wages from caregiving, and even transportation to access services. Participants spoke to how expensive everything about AD is and how difficult it can be to find affordable yet quality care options. For some, expense becomes their greatest concern as the disease progresses and a reason for drastic measures to cover costs, such as selling off assets to qualify for long-term care assistance.

Points of greatest frustration:

- Costs are not well articulated. It is difficult to find information on what costs are covered or where to go for financial assistance.
- Strict criteria for financial aid eligibility.
- Adult day, night care, and non-medical home care are often cost prohibitive.
- Adult day and night care are often not covered by insurance and/or financial aid.
- The care options that are affordable are not always the best quality or do not provide the level of care PWD needs, i.e., memory care.
- More expensive care does not consistently equal higher quality care.
- Limited options for facility placement due to some not accepting Medicaid. If private pay is not an option, families must seek care out of town or out of state.

For long-term care facilities and home health, costs attached to payroll, staff training, and the resources needed to provide the intensive care that PWD require can prevent facilities from providing memory care. Low Medicaid reimbursement rates do not incentivize facilities to admit Medicaid patients or provide memory care. Participants who work in health care administration said it can be hard to keep the doors open, given the low Medicaid reimbursement rates. And as one participant said, memory care facilities that do accept state assistance are "terrible."

Points of greatest frustration:

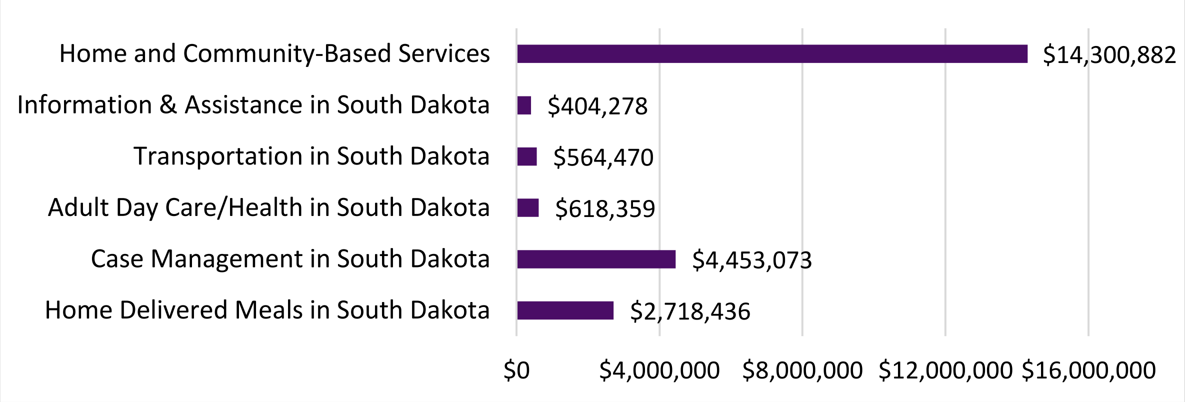
- Stagnant Medicare and Medicaid reimbursement. Excess costs are passed on to residents, where the out-of-pocket costs of care exceed the financial means of PWD.
- Cost of memory care—facility, staff, training—far exceeds reimbursement.

Participants believe funding should support the creation of a model of care that can be easily replicated throughout South Dakota. This model would prioritize affordability, an availability to key resources and services that prioritize the PWD's quality of life, standardized education and training for all professional caregivers, and guidance and support for family caregivers to effectively navigate their PWD's journey with AD.

WHAT FUNDING FOR AD LOOKS LIKE IN SOUTH DAKOTA: STATE EXPENDITURES

The total projected Medicaid costs for South Dakota adults age 65 and older living with Alzheimer's disease or other dementias in 2018 is $167 million. Medicaid costs are projected to increase by 24.3% over the next 8 years, totaling nearly $208 million by 2025. *(Alzheimer's Facts & Figures Report, 2018.*

Total Expenditures for the Adult Day Services (ADS) and Aging Programs and Services (2015)



Currently the State of South Dakota Department of Human Services (DHS) supports six Title III funded ADS programs: Ceili Cottage (Sioux Falls), K.O. Lee Adult Day Health Center (Aberdeen), Avera Sacred Heart Majestic Bluffs Adult Day Services (Yankton), New Hope Adult Day Services (Madison), Shirley's Adult Day Center (Rapid City), and Huron Adult Day Care Center. These programs allow individuals who are age 60 and older an opportunity to donate towards services received, but no fees shall be imposed under the State's agreement with the provider. In addition, the State of SD DHS has additional resources that could be made available to those needing ADS services and are under 60 years old. Eligibility for this funding is determined by LTSS and the Office of Economic Assistance.

Medicaid expenditures by provider type (2017)

Providers with the largest percentage of total Medicaid expenditures in South Dakota in 2016 were hospitals, **nursing homes/assisted living providers**, and DHS/Developmental Disability community support providers.

South Dakota is an income cap state, meaning that to be eligible for Medicaid long-term care benefits there is a hard income limit, no higher than 300% of the Federal Benefit Level of $2,205/month. *(seniorplanning.org, 2017).*

Medicaid provides funding for 55% of the individuals in nursing homes. Home and community-based services (HCBS) waivers are available and allow Medicaid recipients to receive Medicaid funding for in-home care. Home and community-based services are instrumental in reducing nursing home utilization and improving the quality of independent living for seniors. To improve overall long-term services and supports in South Dakota to the highest performing states, it was found that $70,800,000 more would go to HCBS instead of nursing homes. *(Long-Term Services and Supports Scorecard, 2017)*

HCBS Waiver In-Home Services

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2015	454	$4,990,267	$916.00
2016	469	$5,186,582	$922.00
2017	546	$6,728,462	$1,027.00

HCBS Waiver Assisted Living Services

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2015	704	$8,287,850	$981.04
2016	686	$8,376,689	$1,017.58
2017	647	$8,988,059	$1,157.68

Nursing Home Services (DSS only)

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2015	3,252	$136,236,366	$3,491.09
2016	3,167	$141,456,763	$3,722.16
2017	3,039	$140,947,562	$3,864.97

South Dakota Medicaid Report, 2017

HOW EXPENSIVE IS CARE IN SOUTH DAKOTA?

Adult Day Services	$68/day
Home Health Aide	$157/day
Assisted Living	$3,570/month; average of $1,150 annual addition for AD care
Nursing Home	$6,300 for semi-private room/month; $6,813 for private

2017 average rates, Genworth Financials, Inc

REIMBURSEMENT RATES

> *"As a professional caregiver, the reimbursement rates in this state have changed immensely. So much so that if you have someone coming in with dementia and someone with a hip fracture, you'll take the hip fracture because the reimbursement rate is so much higher for that person. I know there are facilities doing this on a daily basis. So where do the people go, and what happens to the caregiver, if they stay in the home? I think there is a possibility for people to remain in the home longer, but the resources are not there because there's limited assistance for that care. There's a huge gap in this state."*

3. THE CURRENT AND PROJECTED SOUTH DAKOTA WORKFORCE NEEDS TO BE ADEQUATELY SIZED AND SKILLED TO MEET THE DEMAND FOR CARE.

CNAs, home health aides, social workers, and other frontline care workers have more direct contact with PWD and their caregivers than any other health care professions. They are responsible for the intensive, daily, hands-on care PWD require in the home and in a long-term care facility. Participants spoke of a gap between what South Dakota currently has for a health care workforce and what is needed to provide quality care. Despite the essential roles these professions play on the AD care team, participants described them as low-pay positions, with minimal AD education provided in the workplace, little opportunity for advancement, and high stress. They see these factors contributing to high burnout and turnover rates in the field, which result in inconsistent quality of care and interaction with PWD—factors that can compromise PWD's wellbeing.

If professional caregivers are valued through fair compensation for their work and learn how to skillfully handle the unique challenges of caring for a PWD, participants think these caregivers may be more inclined to see the value in their work. As a result, burnout and turnover rates could be mitigated.

The absence of AD specialists and trained physicians throughout most of South Dakota also surfaced during discussion on workforce. The University of South Dakota offers the only baccalaureate gerontology program in the state, meaning that specialty presence in the state is largely dependent upon out-of-state recruitment. This expertise was identified as a need by caregivers who expressed needing professional AD or senior care expertise on their side upon diagnosis to help decide the appropriate level of care and for medication management.

Without accessible medical expertise on AD, diagnoses have been delayed and, in some cases, missed entirely. Delay in early and accurate diagnosis brings real consequences to the PWD and their family, such as increased difficulty in arranging necessary legal and financial matters, frustration with handling AD symptoms and behaviors without professional guidance or drug and non-drug interventions, and missed cost savings.

Sioux Falls has the most AD expertise within its health care community in South Dakota. Even so, participants see the need for a more AD educated and trained workforce. In smaller and rural communities, access channels to specialists that work with AD are particularly limited, such as for geriatricians, neurologists, psychiatrists, and primary care physicians with AD training. Attempts to rotate specialists amongst rural communities have not met participant expectations and the wait times for primary care and specialist appointments in larger communities have discouraged PWD from accessing care in a timely manner, making a continuum of care experience difficult to realize.

The need for workforce development is statewide. Staffing of facilities is a problem that exists today. With more jobs open than people to fill across many industries—health care in particular—, participants see the demand for workers to staff home health agencies and long-term care facilities well exceeding current capacity. Participants expressed concern as to what this gap in workforce means for South Dakota's aging population in general and AD population especially.

Health Care Workforce: Current and Projections

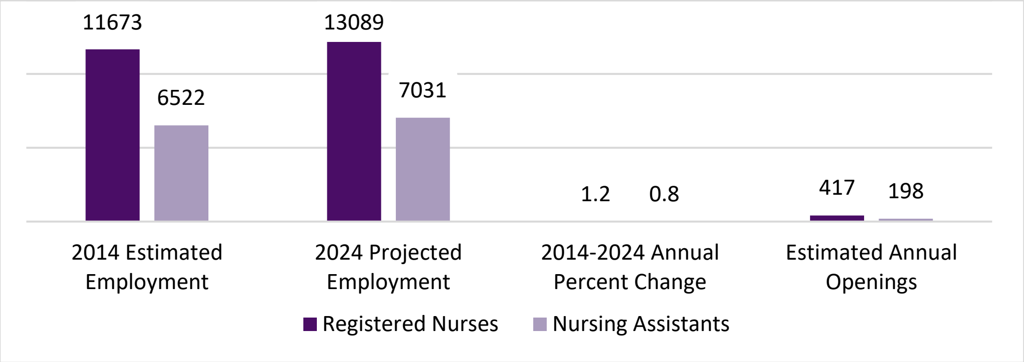
In South Dakota, the level of health professional who often cares for older adults and those diagnosed with AD include nurses (RNs), licensed practical nurses (LPNs), certified nursing assistants (CNAs), home-health aides, physicians, nurse practitioners, and physician assistants. Participants refer to them as the *Care Team.*

Home-health aides and CNAs are expected to be among the nation's fasted growing in-demand occupations. The Department of Labor's economists expect about a million more positions will be added from 2014 to 2024. The critical challenge at hand nationally is how to turn these minimum-wage, direct-care jobs into higher-quality and better-paid positions that can attract the millions of new workers who will be needed to meet the demand. *(New York Times, 2017).* It is suggested that South Dakota would need 3,101 more home health and personal care aides available to improve its performance to the level of the top-five-performing states. *(Long-Term Services and Supports Scorecard, 2017)*

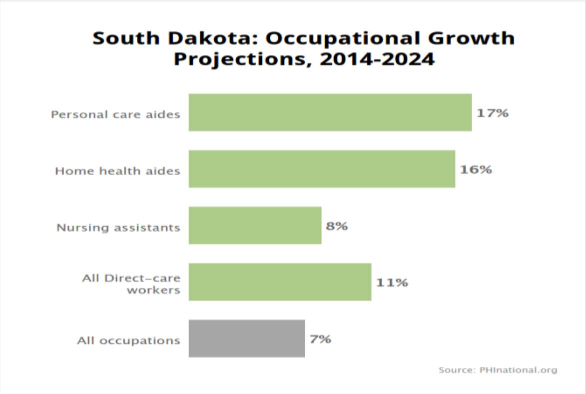
Majority employment settings from January 1,2015-December 31,2016

(SD nursing workforce)	RN (17,693)	LPN (2,549)
Hospital settings	48.9%	9.9%
Ambulatory care	13.4%	17.4%
Long-term care	9.1%	29.0%
Community/home health	n/a	10.3%

Estimated Annual Openings, South Dakota (2014-2024)



Labor Market Information Center, SD Dept. of Labor & Regulation, 2014

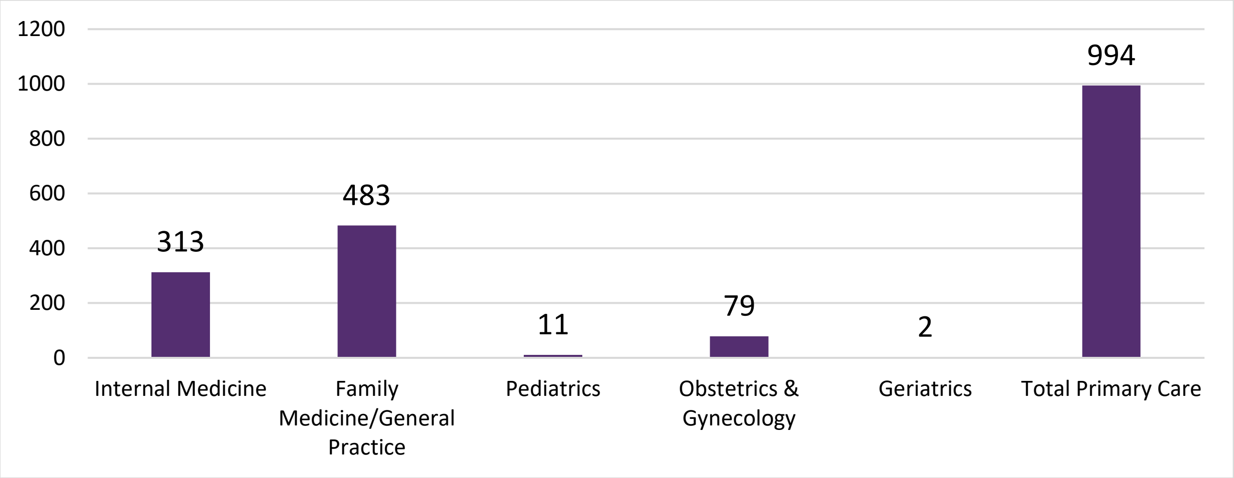


Long-term care projections for the Health Care and Social Assistance Industry show a 10.6% change from 62,395 in 2014 to 68,992 in 2024.

This industry will stand to be supported by technological advancements that may allow more adults to live longer in the home at a lower cost but will not be replaced by increased automation.

PRIMARY CARE PHYSICIANS BY FIELD IN SOUTH DAKOTA, APR-17

Figure 1: Red-Data, Inc., Special data request on State Licensing Information from Redi-Data, Inc., April 2017. Accessed from the Kaiser Family Foundation website, https://www.kff.org/state-category/providers-service-use/physicians/



GERIATRIC MEDICINE SHORTFALL

With the projected increase in the South Dakota population 65 years of age or older in 2030, an estimated 55,519 (30%) will be most vulnerable. It is projected that 79 Geriatricians will be needed in 2030. Between now and 2030, 65 geriatricians need to be trained to meet the need and gaps in care. Just 6% of the 68 clinical nurse specialists and 1.8% of the 848 certified nurse practitioners practice in Gerontology in South Dakota. *(South Dakota Center for Nursing Workforce, 2017)*

GERIATRICIAN EDUCATION IN SOUTH DAKOTA

- Physician: Geriatrics Fellowship Program through The University of South Dakota Sanford School of Medicine.
- Nursing:
  - Eight baccalaureate degree programs.
    - All include curriculum components guided by the American Association of the Colleges of Nursing, Recommended Competencies and Curricular Guidelines for the Nursing of Older Adults.
    - South Dakota State University undergraduate nursing curriculum include concepts related to neurological changes with aging, including AD.
    - Presentation College includes one theory course on Neurocognitive Disorders, including AD. Students spend at least six clinical hours working with patients in a long-term care or memory unit.
  - Six practical nursing programs.
  - Three associate degree programs.
  - Seventeen approved nursing programs.

National limits on geriatric education include: shortage of time spent in training curriculums, low student demand, and lack of geriatric-trained educators. (*Bardach, S. H., & Rowles, G. D. (2012). Geriatric Education in the Health Professions: Are We Making Progress? The Gerontologist.)*

4. Professional care providers and family caregivers need education and training to improve care quality and administrative efficiencies.

43.2% of survey respondents identified the education and training of health care professionals and caregivers as one of the most pressing needs for persons impacted by AD in South Dakota. In all fifteen focus groups, education and training—or lack thereof—was spoken of critically in the following ways:

- Why it is important to have a state plan on AD.
- Service or resource missing that would improve care.
- Significant barrier to access services/resources.
- A point of significant value when available.
- Recommendation for improving the care of PWD in South Dakota.

Participants believe that health professionals at all levels of care are unprepared to address AD—and resort to guessing much of the time. Whether it is the primary physician that addresses the first symptoms and diagnosis of AD, or the CNA or home health aide that is responsible for comfort care and behavior management as the disease progresses, participants are not confident in the level of education and training professionals possess. Participants who identified as health professionals working in the field of AD expressed doubt of their own care competencies and called for additional training through the workplace to become more adept for the sake of quality patient care and career longevity.

Participants recognize the complexity and difficulty of providing AD care and propose a concentrated, ongoing AD curriculum that equips care providers to be competent, agile, and able to meet PWD and their caregivers where they are at. Participants also called for professions that have a more indirect connection to PWD—dentists, optometrists, pharmacists, financial advisors, lawyers—to at the very least be able to recognize symptoms and appropriately work with PWD. Training would include how to respond and adjust their practice to uphold the safety, dignity, and best interests of PWD.

Family caregivers also need education and training. Participants who identified as family caregivers shared that they knew very little themselves and were educated very little upon diagnosis. They reported trouble in determining how best to care for the PWD in the home, when/if to transition to a long-term care setting, and how to make use of limited community services. They did not know enough to make informed care decisions in the PWD's best interest. They were unprepared to handle the emotional, financial, and physical toll of caregiving. Without proper education and training available, the PWD under their care is not able to thrive to the best their condition allows. And caregivers report exhaustion and a decline in the quality of their own lives. 41.5% of survey respondents noted that caregiver education and training were the most helpful resources available to them. Financial support for caregivers to get the training they need was identified as a significant need.

In addition to improving the quality of AD care and reducing frustration of professional and family caregivers, participants see increased education and training as a critical means to slow disease progression and extend a PWD's quality of life. An AD competent caregiving community can lead to an increased rate of early diagnosis, appropriate care intervention, and help to minimize stigma by increasing awareness and understanding.

PARTICIPANT INPUT ON AD EDUCATION AND TRAINING IN SOUTH DAKOTA

Participants set the priority of developing standardized education and training for professional and family caregivers. Education and training were top of mind for participants and discussion surfaced many recommendations as to who should be educated and trained, who should be responsible for its delivery, how it could be offered, and topics that need to be covered. The following are recommendations and ideas that were mentioned in two or more focus groups and in survey responses.

Who should be educated?

Patients	Students	SD politicians and legislators
The public/community	All care workers (CNAs to MDs)	Specialists
Families	Hospital/facility administrators	All who work with AD
Caregivers		

Who should be responsible for education and training?

Senior centers	Physicians	Professional AD Educator
Churches	Long-term care facilities	Middle & high schools
Clinics	Government	Colleges and universities
Alzheimer's Association	Home health agencies	

Modes of delivery:

Alzheimer's Association	At the time of diagnosis	Distribute online
Take-home reading material	Through the workplace	Annual AD state conference
Local educational events	Care provider's offices	Concise and clear information
Seminars for professional and family caregivers	Mandatory continuing education credits (CEUs)	Centralized place to go to find resources and services

Education and training topics for families/family caregivers:

Caregiving techniques	Progression of the disease/what to expect
Safety measures	How to manage challenging behaviors
What to do first	Recognition of the disease; early indicators
How to cope with the stressors of caregiving	Where to go for education and support
How to access services and resources	Creative care solutions
Associated financial and legal matters	Hand-in-Hand training through CMS

Education and training topics for professional caregivers:

Manage behavioral issues and crisis response	Care options; home health or facility placement
How to effectively interact with PWD	Difference between AD resident & general pop
How to best communicate with families	AD is not a normal part of aging
Diagnostic training on all types of dementia	Alternative therapies
Pharmacology/medication management	Available community resources and referrals

Participants did not focus on strategizing how to bring increased education and training to South Dakota, but did emphasize that it must be easily accessible, well-publicized, and affordable to be effective on a statewide scale and bring about meaningful improvement in the quality of care provided.

5. SOUTH DAKOTA NEEDS TO REFRAME HOW AD IS UNDERSTOOD, PERCEIVED, AND CARED FOR THROUGHOUT THE STATE TO REDUCE STIGMA AND IMPROVE THE QUALITY OF LIFE A PWD EXPERIENCED.

Survey respondents rated their satisfaction with public awareness a 2.7 (on a scale of 1-5) with room for improvement. Throughout focus group discussion, the call for increased community awareness and support was framed as a way reduce the stigma attached to AD in South Dakota and open the issue up for expanded discussion at all levels: in the home, in the community, and at the state level.

AD stigma can be seen in many ways:

- Individuals are reluctant to acknowledge memory concerns and related symptoms.
- Families are embarrassed and/or afraid of an AD diagnosis.
- Family caregivers do not want to accept help and are slow in doing so.
- Physicians delay evaluation/diagnosis.
- Home health care is not touted as a viable, long-term care option.
- Long-term care facilities are ill-equipped to provide the type of care PWD need.
- Community services and resources are not well-known or sufficient.
- The public chalks it up to “old age.”
- Lack of public recognition of Disease status (not just “normal” aging).
- State Officials have not prioritized the condition of AD, its diagnosis, or its care even though education opportunities exist annually during session and throughout the year.

Stigma—matched with a lack of public awareness and support—can be detrimental for PWD and their families and allows the disease to grow behind closed doors. Participants see an increase in public awareness and support as an essential part of improving the care of PWD in South Dakota and improving their overall quality of life.

With more awareness comes a larger network of support to aid in the care of PWD and reduce the burden on both family caregivers and the health care community.

Looking forward, participants want South Dakota to understand AD and rally behind it by endorsing the need for public awareness and support.

> *“One client told me, ‘this is embarrassing, I wish I had cancer.’ With other diseases, people wear pink and fight for the cause, but with this disease, people leave town, so no one has to see them with this disease. We do not have awareness or a road map for how this disease will progress and that can be scary.”*

STATEWIDE NEEDS ASSESSMENT PARTICIPANT OVERVIEW

147 | focus group participants

Participants per region

58 | Region 1—Sioux Falls and Brandon
24 | Region 2—Rapid City and Spearfish
15 | Region 3—Pierre, Chamberlain, and Mobridge
19 | Region 4—Mitchell, Yankton, and Vermillion
31 | Region 5—Aberdeen, Brookings, and Watertown

**Focus groups averaged 10 participants per session.*

1,025 | survey respondents

The respondent base is shaped by the following points:

→ General demographic information:

- 95.6% | white.
- 79.0% | female.
- 60.0% | represent 5 of 66 counties (Minnehaha, Pennington, Lincoln, Brown, Fall River)
- 67.0% | between 45 and 74 years of age.
- 61.9% | employed full-time.
- 58.0% | household income between $50,000 and $149,999.
- 36.6% |health care providers.

→Specific points related to AD:

- Primary connections to AD.
    1. 43.0% | son, daughter, or other family member of a PWD.
    2. 33.4% | currently work or have worked with PWD.
- Secondary connections to AD.
    1. 42.5% | Know or have known a PWD.
    2. 25.7% | Friend or acquaintance of a PWD.
- 58.1% | have either been a family/friend or professional caregiver.
- 69.3% | familiar or somewhat familiar with AD care and resources in SD.

It is reasonable to assume these points are representative of the total needs assessment sample.

To obtain a copy of the South Dakota Alzheimer's Disease and Other Dementias Needs Assessment, contact the Alzheimer's Association's South Dakota Chapter.

GLOSSARY OF TERMS*

AD: Alzheimer’s Disease or Other Dementias.

Assisted Living center: Licensed by the state to provide personal care and services beyond basic food, shelter, and laundry. May admit and retain only those who do not require more than intermittent nursing care by a licensed nurse. May provide home health agency services for short term skill services for a specific medical reason.

Caregiver: Anyone who provides care to a person with Alzheimer's disease or other dementias. Caregivers can be family members, friends, or paid professional caregivers. Caregivers may provide full or part-time help to the individual with dementia.

- Paid professional caregivers work in hospital, residential, and home settings. Depending on the level of care provided, they are direct care providers or professional practitioners.

Chronic disease: According to the U.S. National Center for Health Statistics, a chronic disease is one persisting for a long time (usually three months or more) and generally cannot be prevented by vaccines or cured by medications, nor do the symptoms disappear on their own. Health-damaging behaviors—particularly tobacco use, lack of physical activity, and poor eating habits—are major contributors to chronic disease.

Dementia: Dementia is not a specific disease. Instead, dementia describes a group of symptoms associated with a decline in memory, thinking, and social abilities severe enough to reduce an individual’s ability to perform everyday activities. Alzheimer's disease is the most common type of progressive dementia in older adults, yet there are several types of dementia.

Geriatricians: Physicians concerned with the diagnosis, treatment, and prevention of disease in older adults. They specialize in managing conditions specific to aging, including dementia.

Guardian: Guardianship is established by a court order. The court grants the guardian authority and responsibility to act on behalf of another person. The relationship is fiduciary, which means that the guardian is obliged to act in the best interest of the individual for whom he/she is a guardian.

Home health agency: certified by Medicare to provide nursing services in the home to persons who require intermittent nursing care.

Hospice: A hospice program offers support for dying individuals and their family members to live as fully and comfortably as possible. Hospice care is generally provided to individuals with a life expectancy of six months or less. Rather than seeking a cure, hospice care aims to make an individual’s remaining time as comfortable and as meaningful as possible. Hospice is a Medicare benefit.

Long-term care facility: A long-term care facility is a nursing home or assisted living center designed to provide a variety of services, including both medical and personal care, to individuals who are unable to manage independently in the community. Many residents in long-term care facilities have dementia.

Long-Term Services and Supports (LTSS): Provides home and community-based service options to individuals 60 years of age and older and 18 years of age and older with disabilities.

Medicaid: Medicaid is 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.

Medicaid waiver: States can use the waiver process to test new or existing ways to deliver and pay for health care services in Medicaid and the Children's Health Insurance Program (CHIP). There are four primary types of waivers and demonstration projects, one of which is the Section 1915(c) Home and Community based Services Waiver.

Medicare: Medicare is a federally-funded government health insurance program for people aged 65 and older and for certain younger individuals with disabilities.

Memory Care or Alzheimer's Special Care Unit (SCU): SCUs are designed to meet the specific needs of individuals with Alzheimer's and other dementias. SCUs can take many forms and exist within various types of residential care. Including assisted living facilities, and they may or may not be locked or secure units. Such units most often cluster settings in which persons with dementia are grouped on a floor or a unit within a larger residential care facility.

Nursing facility: Licensed by the state; may be certified by Medicare and/or Medicaid. May admit and retain those who require nursing care by licensed nurses. Have a medical director and staffed with licensed nurses.

Palliative care: Palliative care includes medical and/or surgical methods to ease the pain and other distressing symptoms of a serious or incurable illness.

Person-centered care: This term refers to health care 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.

PWD: Person or people living with a dementia.

Respite care: 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.

Rural and frontier communities: For the purposes of this plan, rural communities in South Dakota were those with a total population of less than 25,000.

Urban communities: For the purposes of this plan, urban communities in South Dakota were those with a total population of more than 25,000 and/or with full-service hospitals and hospital staffs with multiple specialists. Criteria considers Brookings, Mitchell, Rapid City, Sioux Falls, Watertown, and Yankton to be urban communities.

**In part adopted from Montana's AD State Plan.*