

South Dakota

Alzheimer’s Disease and Related Dementias Needs Assessment

A report for the South Dakota Alzheimer’s Disease and Related Dementias Work Group.

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Process Overview

Maximizing Excellence, LLC (MELLC) was contracted to provide the Alzheimer’s Association South Dakota Chapter the expertise needed to facilitate the development of a South Dakota Alzheimer’s and Related Dementias (ADRD) State Plan. The following objectives were set for MELLC to accomplish that work:

1. Formalize the South Dakota ADRD State Plan Work Group.
2. Conduct a statewide needs assessment.
3. Create a comprehensive summary report to enlighten the development of a state plan.

History:

South Dakota is one of four states without an ADRD state plan. Need for a state plan was identified in 2015 by Alzheimer’s Association South Dakota Chapter leadership. State plans have typically been pursued in one of two ways: 1) through grass-roots efforts; or 2) through a state sponsored task force. When the issue was brought before the South Dakota State Legislature during the 2016 session, it was determined that an ADRD state plan would best be founded through a non-legislative work group with guidance from the Alzheimer’s Association South Dakota Chapter.

Objective 1: Formalize the South Dakota ADRD State Plan Work Group

The South Dakota ADRD State Plan Work Group formally convened in April 2017. The voluntary work group is comprised of 21 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 ADRD care in South Dakota for individuals living with the disease and their caregivers.

Criteria for work group selection included proximity to and experience with ADRD, 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 ADRD, reviewing and approving methodology and materials, and ultimately engaging in state plan development under close guidance of the South Dakota ADRD needs assessment.

Work Group Roster

Dr. James Barker	Brandy Fiala	Molly Keegan
Dean Bertsch	LaVonne Gaspar	Leslie Morrow
Dr. V.R. Brandenburg	Nathan Gelhaus	Secretary Gloria Pearson
Dr. David Brechtelsbauer	Lisa Griffin	Edith Renner
Dr. Oluma Bushen	Tom Herges	Brad Richardson
Holly Carr	Kathi Herreid	Jennifer Rosen
Peggy Cruse	Lori Hintz	Diana Swier

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

Process Overview

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 ADRD 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 make sure the needs assessment would be a representative snapshot of ADRD 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 ADRD at all levels, including any stigma associated with ADRD.
- The adequacy of education and training available for anyone associate with ADRD.
- How ADRD 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 ADRD 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—flyer, ad, and news release—that explicitly stated what the focus groups aimed to do and who the ideal participant would be. A connection to ADRD, 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.

Process Overview

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 ADRD 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 ADRD. In total, 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 ADRD either through the Alzheimer's Association 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 to these respondents.

Convenience sampling took place through the circulation of paper surveys to places that those touched by ADRD 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 ADRD in South Dakota, rate the quality of ADRD 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.

Process Overview

Objective 3: Create a comprehensive summary report to enlighten the development of a state plan.

MELLC developed survey and focus group content as well as accompanying distribution materials. 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. Alzheimer's Association South Dakota Chapter and the work group provided technical support throughout the process and were the recipients of the report. The report will be the catalyst for developing a comprehensive state plan. The state plan will be presented to the South Dakota State Legislature in hopes of receiving their support for the critical work to be done.

Limitations

Given the urgency of developing a state plan on ADRD, the timeline to complete the needs assessment was aggressive to allow the work group 12 months to develop a state plan informed by the findings and time to prepare their appeal to the South Dakota State Legislature during the 2019 session, which runs January – mid-March. After consulting with those well-versed in tribal community study inclusion, it was determined that the timeline did not allow for tribal communities to be purposefully included in the study outside of the study's broad participant recruitment strategies. Project leadership pledged to involve this perspective and amend the report by the end of 2018.

Special contribution

Work group member James Barker, MD sought to include the poor or uncared in the study. He designed a questionnaire that involved five basic questions about ADRD 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 ADRD.
2. No one had been a personal caregiver for anyone with ADRD, though they know or had a relative who had been.
3. They did not know of the related problems in the caregiver's position.
4. They had not any suggestions for how state or local services could have made the situation better.

He 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 ADRD and need the coordinated and high quality of state services that will be advocated in the plan.

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 ADRD:

- Primary connections to ADRD.
 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 ADRD.
 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 ADRD care and resources in SD.

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

Glossary of Terms*

ADRD: Alzheimer's Disease or Related 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 related 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.

Glossary of Terms* *continued*

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.

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 ADRD State plan.*

ADHD South Dakota Needs Assessment Executive Summary

The needs of people living in South Dakota with dementia (PWD) and those that care for them—whether in a professional or personal capacity—are not being fully met. Frustration exists throughout the entire ADRD community as to how dementia is handled in the state and participants have not been satisfied with the services and resources offered to them.

Participants shared they thought more factors were working against the best interests of PWD than for them. Their collective experience can be summed up into two key takeaways:

1. Services and resources are inadequate or missing throughout the state.

- 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. Participants believe the moratorium prohibits adding beds where they are most needed.
- Assisted living and nursing homes with memory care units exist, but not on the scale that is needed to meet growing demand. Many participants have had to relocate to access memory care or settle with non-specialized care in their area.
- Limited services and resources exist for higher-acuity or higher-care need PWD. Behavioral health and crisis intervention is virtually nonexistent. The only option for many participants was the Human Services Center (HSC) in Yankton as many long-term care facilities evict or do not accept these PWD, leaving families with few options.
- Access to services and resources is significantly compromised in rural and small communities. Getting connected with primary care, specialty services, transportation, workforce, care facilities, caregiver support, funding, and education was reported as difficult and discouraging.
- 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 extend their quality of life. Caregivers consistently reported not knowing where to go or how to access care and support.
- Mandatory and/or standardized ADRD 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 a lack of training. They also shared that having trust in the ability, knowledge, and quality of their care providers is of greatest 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.

ADHD South Dakota Needs Assessment Executive Summary *continued*

2. Where services and resources exist, they are constrained by high costs, insufficient workforce numbers, a lack of knowhow, 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 for the majority. Most memory care is private pay, which has priced out many participants from accessing it. For some participants, their only affordable care 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. And participants have found that these facilities typically limit the number they do 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 memory care, including a lower staff to resident ratio, continuing education for staff, a non-mixed population, and increased security.
 - PWD are placed in settings that are ill-equipped for higher-needs residents due to reluctance to seek a diagnosis, delay of an accurate diagnosis, and lack of knowhow on how to navigate services and resources for PWD. Assisted living facilities and home health agencies have been found too late in disease progression.
 - There are not enough direct care workers for ADRD service and resource providers to adequately staff their operations. Difficulty in finding and retaining qualified staff—above and beyond quantity—compounds the issue. Participants believe statewide workforce development, and the pay scale of CNAs, are at the heart of the issue.
 - The training and education that does exist does not adequately prepare care providers. This includes the baseline of what ADRD 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 improvement in how ADRD is approached in health care.
 - Participants reported that being a family caregiver is financially straining, and emotionally and physically difficult to endure. 77% of survey respondents were somewhat or not familiar with available services and resources, and no one majority point of access to information 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.
 - ADRD is met with significant stigma throughout South Dakota. It is not something 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.

ADHD South Dakota Needs Assessment Executive Summary *continued*

The needs assessment uncovered many gaps but also shed light on areas that participants have seen improvement and/or effectiveness:

- 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 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 ADRD 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.

Care for ADRD is not *what* it needs to be or *everywhere* it needs to be in South Dakota for people living with and amongst the disease to have their best outcome possible. Participants did not see this as a reality unique to South Dakota, but as a real struggle for the country. They were encouraged to learn that other states have taken the initiative to improve the care of PWD through state plans. Participants believe that crafting a plan to meet the needs of South Dakota, while long overdue, is the right next step.

Needs assessment participants did not claim to have all the solutions but did share many common recommendations for improving the state of ADRD care in South Dakota based on the breadth and depth of their collective experience. They are hopeful at the prospect of a state plan and see it as a road map and convener of influence, advocacy, and action.

Top Five Recommendations

Recommendations for improved ADRD care in South Dakota align with the following priorities:

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.
2. Develop funding priorities and strategies to make ADRD services /resources more affordable -for facilities to provide and -for families to access.
3. Execute the necessary steps on state and local levels to develop an adequately sized and skilled ADRD workforce throughout South Dakota.
4. Prioritize the education and training of professional care providers to improve care quality and efficiencies. Provide training opportunities to family caregivers.
5. Reframe how ADRD is understood, seen, and cared for throughout South Dakota to reduce stigma and improve the quality of life a PWD experiences.

A detailed analysis of these recommendations can be found on pages 16-32.

Rationale for a South Dakota ADRD Plan

78.4% of survey respondents reported being concerned to very concerned about how ADRD 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 ADRD 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 ADRD in South Dakota.
2. Increasing aging population in South Dakota.

1. Increasing prevalence of ADRD in South Dakota

As one participant said, *“Everyone is going to be touched by ADRD in some way.”* Participants foresee an increase in the amount of ADRD cases diagnosed annually and with that, an increase in the number of people accessing care. Given their perception that ADRD 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, ADRD 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, 2017).
- Alzheimer’s Disease was the fifth leading cause of death among South Dakota adults from 2011-2015, as well as by race. 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*).

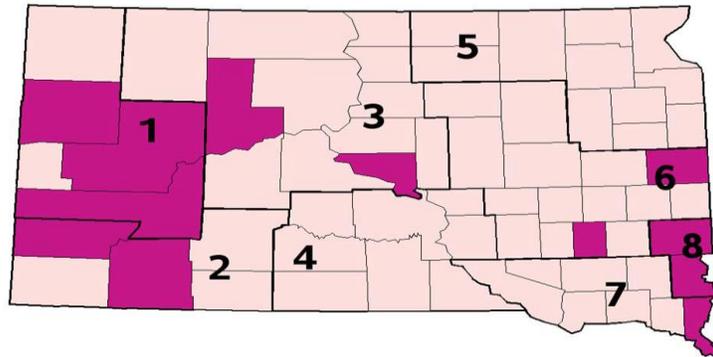
2. Increasing aging population in South Dakota.

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 ADRD and an increase in the majority age demographic (65+) most likely to be diagnosed with ADRD, a state plan on ADRD 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 for a South Dakota ADRD Plan *continued*

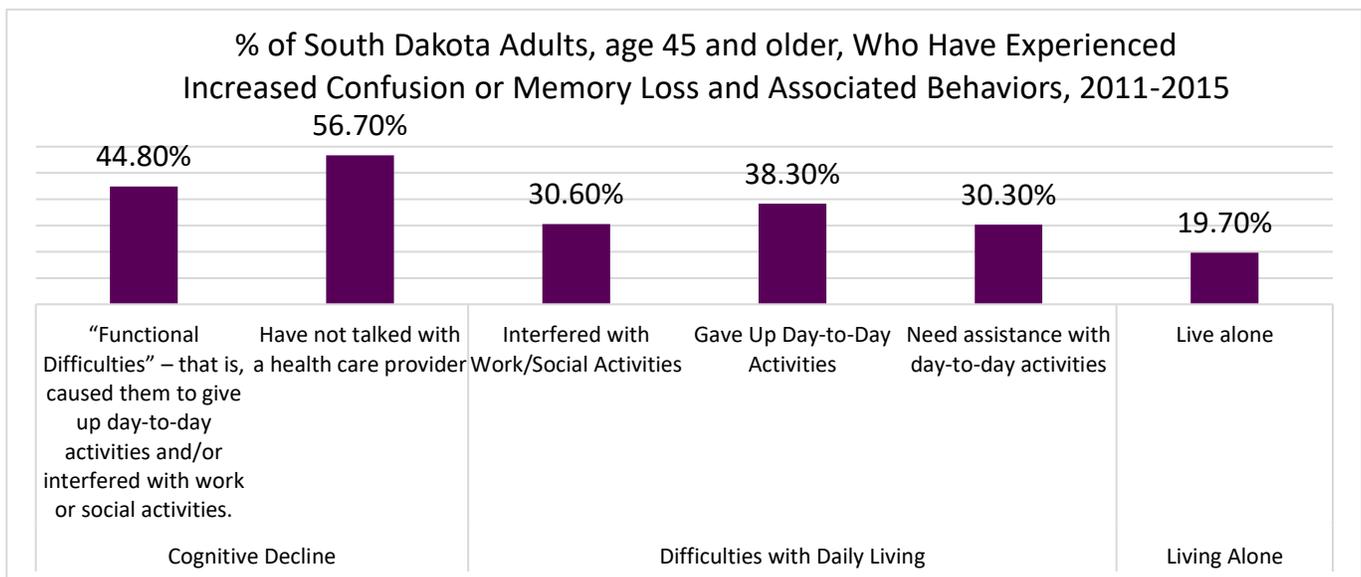
South Dakota counties where the elderly disabled population is expected to double from 2010 to 2035: Brookings, Butte, Custer, Hanson, Hughes, Lincoln, Meade, Minnehaha, Oglala Lakota, Pennington, Union, and Ziebach.



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

Confusion and memory loss in South Dakota

- 15% of South Dakota adults had a primary diagnosis of Dementia in 2017. (*Alzheimer's Facts and Figures, 2017*)
- 6.3% of older 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*)



Snapshot of ADRD care in South Dakota

Satisfaction with ADRD services and resources

Scale of 1-5, 5 being very satisfied

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 ADRD
2.3	Coverage of costs of services and resources

Quality of ADRD care

Scale of 1-5, 5 being excellent

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.)

Snapshot of ADRD care in South Dakota *continued*

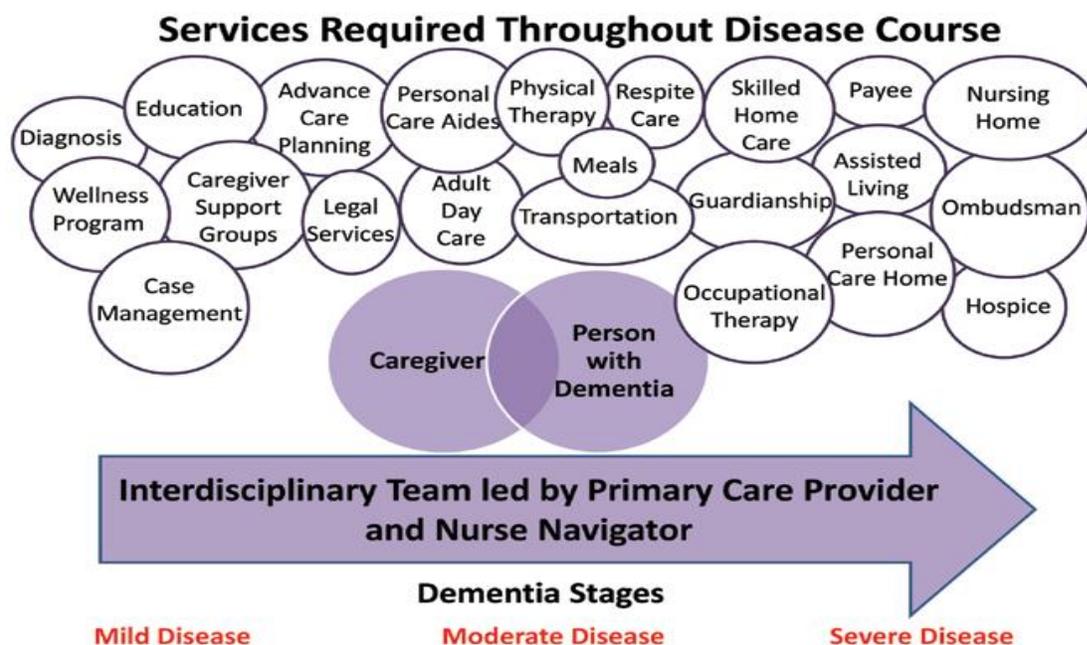
Most pressing needs

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

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 ADRD care

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.

Meeting the Needs of PWD and their Caregivers

1. Ensure Quality Services and Resources are Available 17-23
2. Make ADRD Services and Resources More Affordable 24-26
3. Develop an Adequately Sized and Skilled ADRD Workforce 27-29
4. Prioritize Educating and Training Professional Care Providers 30-31
5. Address Stigma by Reframing how ADRD is Understood and Seen..... 32

1. Ensure quality services and resources are available 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 ADRD 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. As one participant said, it should be a priority to have *"the right care available to the right person at the right time."*

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

- Long-term care facilities:
 - Assisted living, preferably with memory care.
 - Skilled nursing, preferably with memory care.
 - Hospice.
 - Home health care.
- Health care supports and auxiliary services:
 - Care providers: primary care, mental and behavioral health, geriatricians, etc.
 - Access to ADRD 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:
 - ADRD-friendly public spaces.
 - ADRD-aware representatives from professions that work with PWD and their families, including emergency, financial, legal, and retail services.

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Long-term care in South Dakota

According to the 2017 AARP state scorecard on long-term services and supports, 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 amongst care experiences and facilities, and facilities that are designed to respond to the unique needs of ADRD residents.

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 ADRD 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.

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

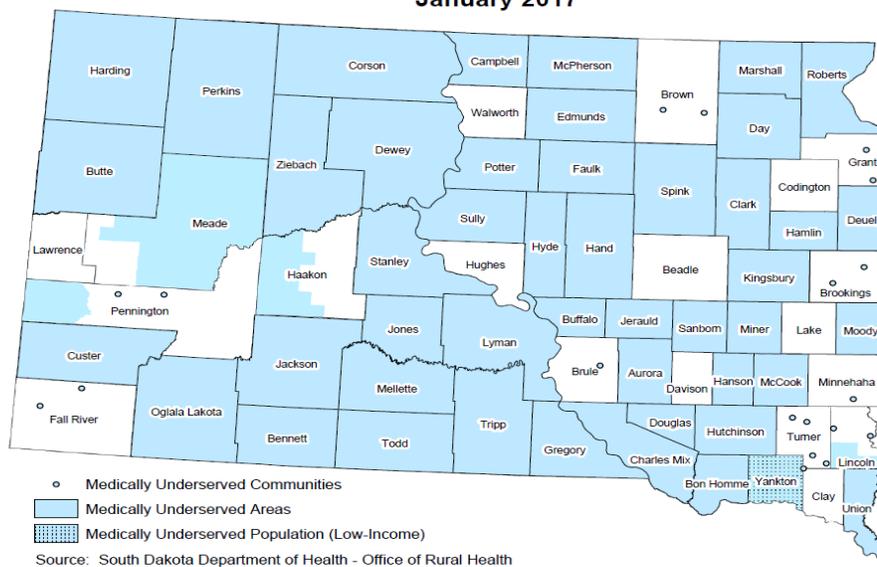
Health care supports and auxiliary services

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



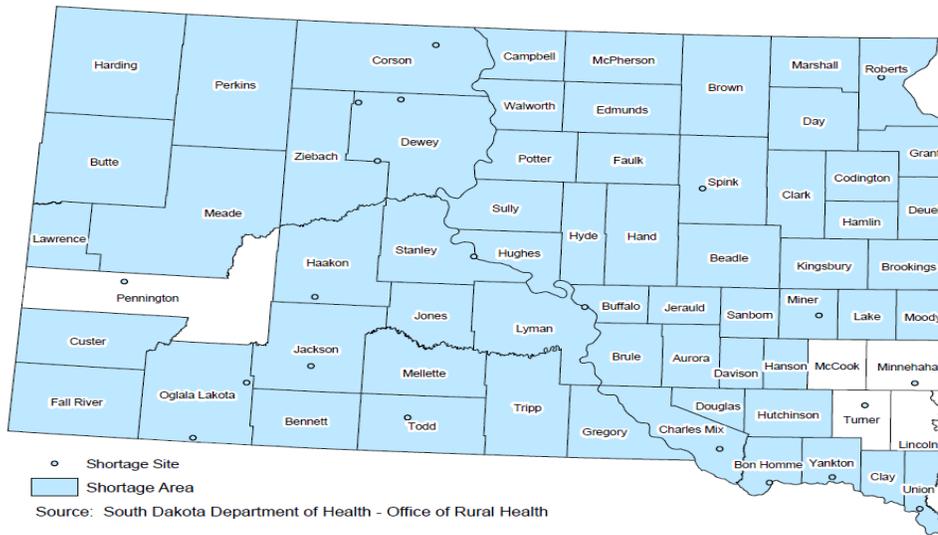
Participants report that limited access to health professionals and medical services negatively affect the quality of life a PWD and their caregiver experiences.

Participants living in underserved and shortage areas reported having to travel more than one hour and up to three for appointments that usually necessitate follow-ups. 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 ADRD 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.

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

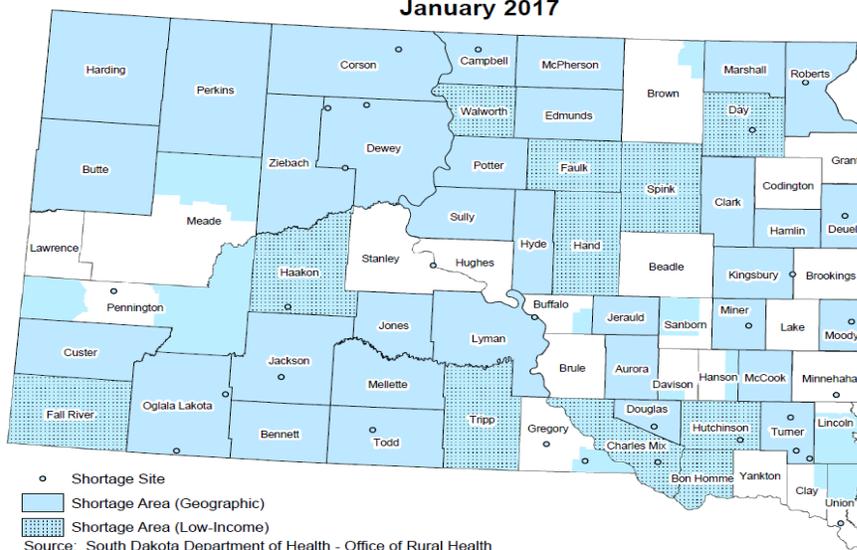
**SOUTH DAKOTA HEALTH PROFESSIONAL SHORTAGE AREAS
MENTAL HEALTHCARE
January 2017**



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 ADRD.

Undiagnosed PWD have been sent to jail because first responders do not know how to identify the behavioral symptoms of ADRD. 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**



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

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

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

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). (*Source: Alzheimer's Facts & Figures 2017*)
- Caregivers in South Dakota have higher health care costs at \$27 million. (*Source: Alzheimer's Facts & Figures 2017*)
- In 2015, \$770,572 was expended for caregiver's respite care in South Dakota. (*Source: 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, and preparedness for disease progression.

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 Long-Term Services and Supports program is seen as a valuable program for administration of caregiver support but riddled with limitations on service area and use.

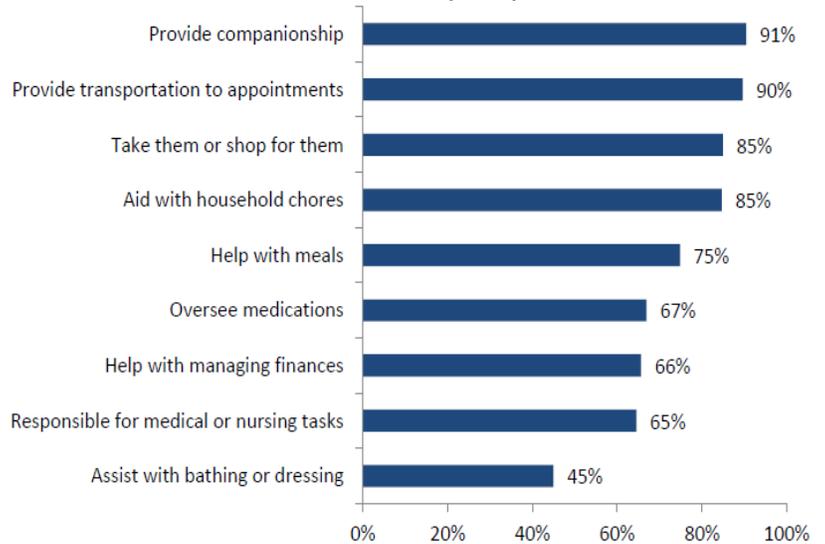
Other caregiver supports that surfaced included financial and legal preparation and planning, education and training, and the Alzheimer's Association South Dakota Chapter.

What family caregiving looks like in South Dakota (nonspecific to ADRD)

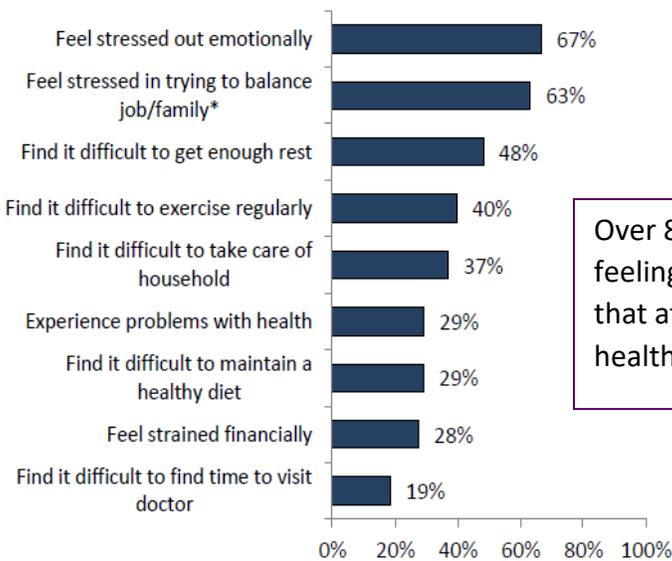
Findings from the AARP South Dakota Caregivers Survey, 2017

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

Caregiving Activities of Current or Former Caregivers (n=471)



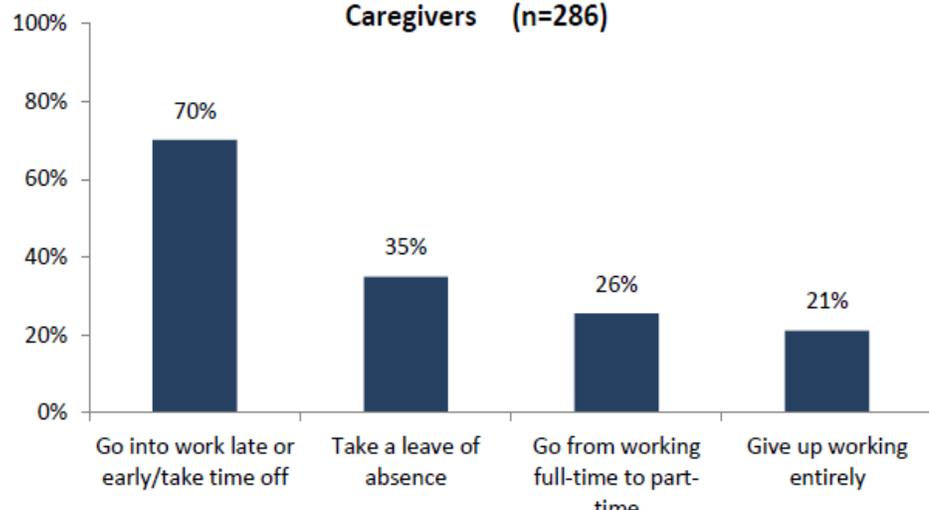
The Emotional Stress of Caregiving (Current & Former Caregivers; n=471)



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.

Work Impacts Experienced by Current & Former Working Caregivers (n=286)



1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

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 ADRD.
- 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 ADRD efforts.
- Church groups and coffee groups that welcome their friends with ADRD.
- The ministerial associations are supportive emotionally.
- Meals on Wheels keep ADRD patients living at home engaged.
- Some home health agencies 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. Develop funding priorities and strategies to make ADRD services and resources 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 ADRD. An ADRD 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 ADRD 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 and night care and home health 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 provide the level of care the PWD needs, i.e., memory care.
- More expensive care does not equal higher quality or more effective 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 disable facilities from providing memory care. Low Medicaid reimbursement rates do not incentivize facilities to admit Medicaid patients or provide memory care at all. Participants who work in health care administration said it can be hard to keep the doors open with how low rates are. 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 and capacity.

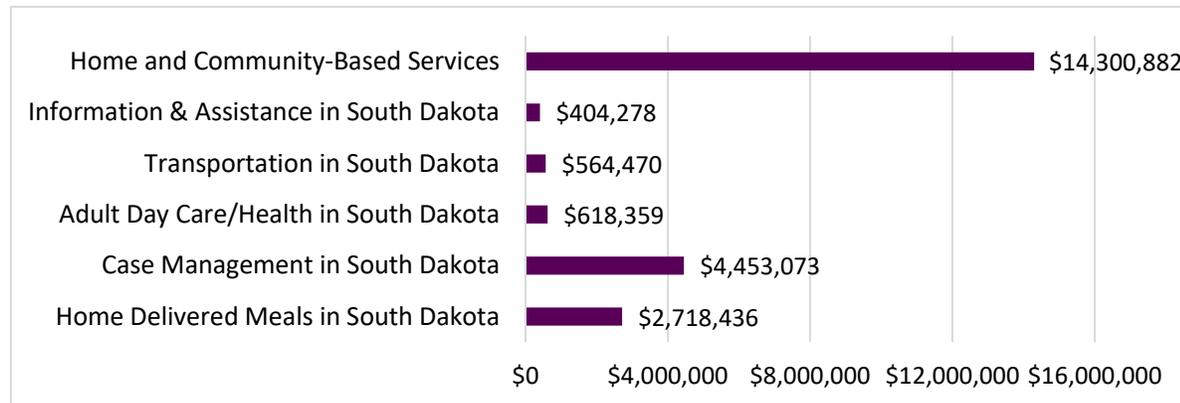
Participants believe funding should support the creation of a model of care that can be easily replicated throughout South Dakota. This model would prioritize affordability, an availability to key resources and services that prioritize the PWD’s quality of life, standardized education and training for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

What funding for ADRD 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 Dementia in 2017 is \$157 million. And is projected to be \$205 million in 2025, a 30% increase in expenditures over the next 8 years. *(Source: Alzheimer’s Facts & Figures - 2017, U.S. Centers for Medicare & Medicaid Services)*

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



Medicaid expenditures by provider type (2016)

Providers with the largest percentage of total Medicaid expenditures in South Dakota in 2016 were hospitals, **nursing homes/assisted living providers**, and Department of Human Services/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 (HCBS) waivers are available and allow Medicaid recipients to receive Medicaid funding for in-home care. Home and community-based services are instrumental to reducing nursing home utilization and improving the quality of independent living for seniors.

HCBS Waiver In-Home Services

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2014	414	\$4,072,132	\$820.00
2015	454	\$4,990,267	\$916.00
2016	469	\$5,189,582	\$922.00

HCBS Waiver Assisted Living Services

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2014	688	\$7,808,825	\$945.84
2015	704	\$8,287,850	\$981.04
2016	686	\$8,376,689	\$1,017.58

Nursing Home Services (DSS only)

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2014	3,332	\$126,812,527	\$3,171.58
2015	3,252	\$136,236,366	\$3,491.09
2016	3,167	\$141,456,793	\$3,722.16

South Dakota Medicaid Report, 2016

How expensive is care?

Adult Day Care	\$68/day
Home Health Aide	\$157/day
Assisted Living	\$3,570/month; average of \$1,150 annual addition for ADRD 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 aren’t there because there’s limited assistance for that care. There’s a huge gap in this state.”

3. Execute the necessary steps on state and local levels to develop an adequately sized and skilled ADRD workforce throughout South Dakota.

CNA's, 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 ADRD care team, participants described them as low-pay positions, with minimal ADRD 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 see they are valued through fair compensation for their work and learn how to handle the unique challenges of caring for a PWD better, participants think they may be more inclined to see the value in their work and burnout and turnover rates could be mitigated.

The absence of ADRD specialists and trained physicians throughout most of South Dakota also surfaced during discussion on workforce. There is only one baccalaureate gerontology program offered in South Dakota, 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 ADRD 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 ADRD, diagnoses have been delayed and in some cases, missed entirely. Delays in diagnosis bring real consequences to the PWD and their family, such as increased difficulty in arranging necessary legal and financial matters, and frustration with handling ADRD symptoms and behaviors without professional guidance or care.

Sioux Falls has the most ADRD expertise within its health care community in South Dakota. Even so, participants see the need for a more ADRD educated and trained workforce. In smaller and rural communities, access channels to specialists that work with ADRD are particularly limited, such as for geriatricians, neurologists, psychiatrists, and primary care physicians with ADRD 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 ADRD 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 ADRD 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 fastest 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)

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)

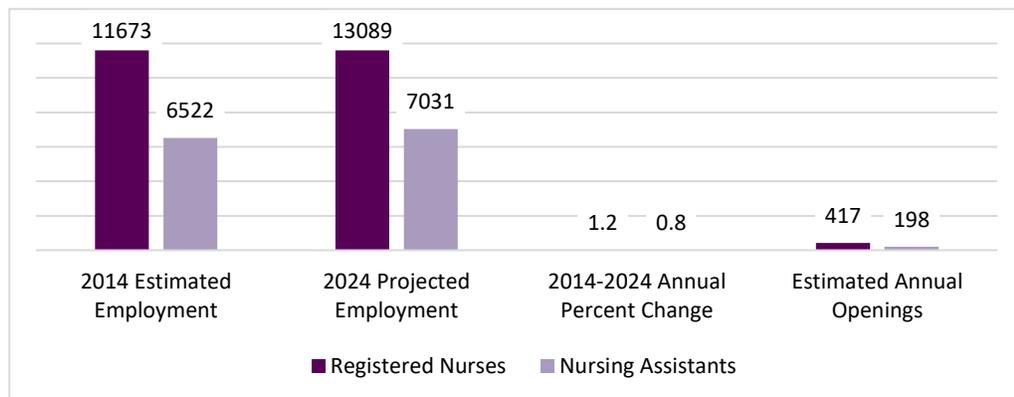
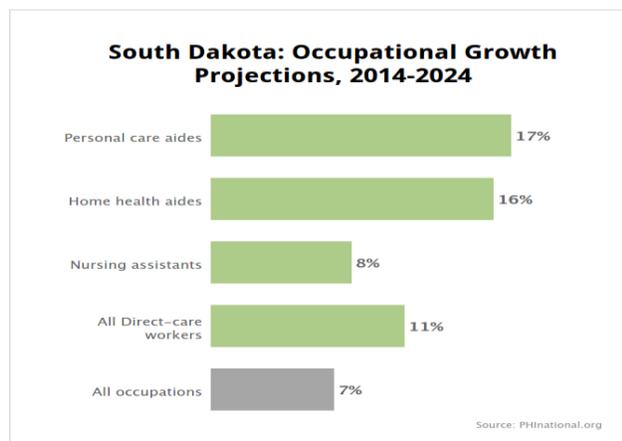


Figure 1 Labor Market Information Center, SD Dept. of Labor & Regulation, 2014



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.

South Dakota Health Care Workforce Current and Projections

Primary Care Physicians by Field in South Dakota, Apr-17

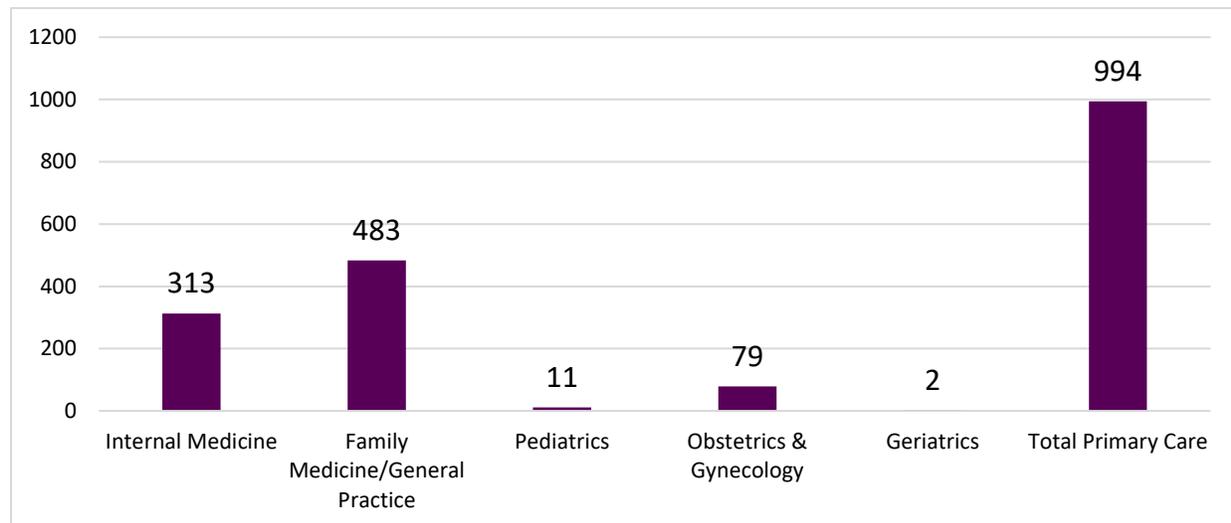


Figure 2: Red-Data, Inc., Special data request on State Licensing Information from Redi-Data, Inc., April 2017. Accessed from the Kaiser Family Foundation website, <https://www.kff.org/state-category/providers-service-use/physicians/>

Gerontology 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 Program through The University of South Dakota medical school.
- Nursing:
 - Eight baccalaureate degree programs.
 - All include curriculum components guide 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 ADRD.
 - Presentation College includes one theory course on Neurocognitive Disorders, including ADRD. 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. Prioritize the education and training of professional care providers and family caregivers to improve care quality and 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 ADRD 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 ADRD.
- Service or resource missing that would improve care.
- Significant barrier to access services/resources.
- A point of significant value when shown.
- Recommendation for improving the care of PWD in South Dakota.

Participants believe that health professionals at all levels of care are unprepared to address ADRD- and resort to guessing much of the time. Whether it is the primary physician that addresses the first symptoms and diagnosis of ADRD, 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 ADRD 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 ADRD care and propose a concentrated, ongoing ADRD 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 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 ADRD 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 ADRD 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 ADRD 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 ADRD
Caregivers		

Who should be responsible for education and training?

Senior centers	Physicians	Professional ADRD 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 ADRD state conference
Local educational events	Care provider's offices	Concise and clear information
Seminars for professional and family caregivers	Mandatory continuing education credits	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 ADRD resident & general pop
How to best communicate with families	ADRD 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 a meaningful improvement in the quality of care provided.

5. Reframe how ADRD is understood, seen, and cared for throughout South Dakota to reduce stigma and improve the quality of life a PWD experiences.

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 ADRD 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.

ADRD 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 ADRD diagnosis.
- Family caregivers do not want to accept help and are slow in doing so.
- Physicians delay evaluation/diagnosis.
- Home health 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.”
- State Officials have not prioritized the condition of ADRD, 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 ADRD 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 don’t have awareness or a road map for how this disease will progress and that can be scary.”

Focus Group Findings by Region

Region 1.....34

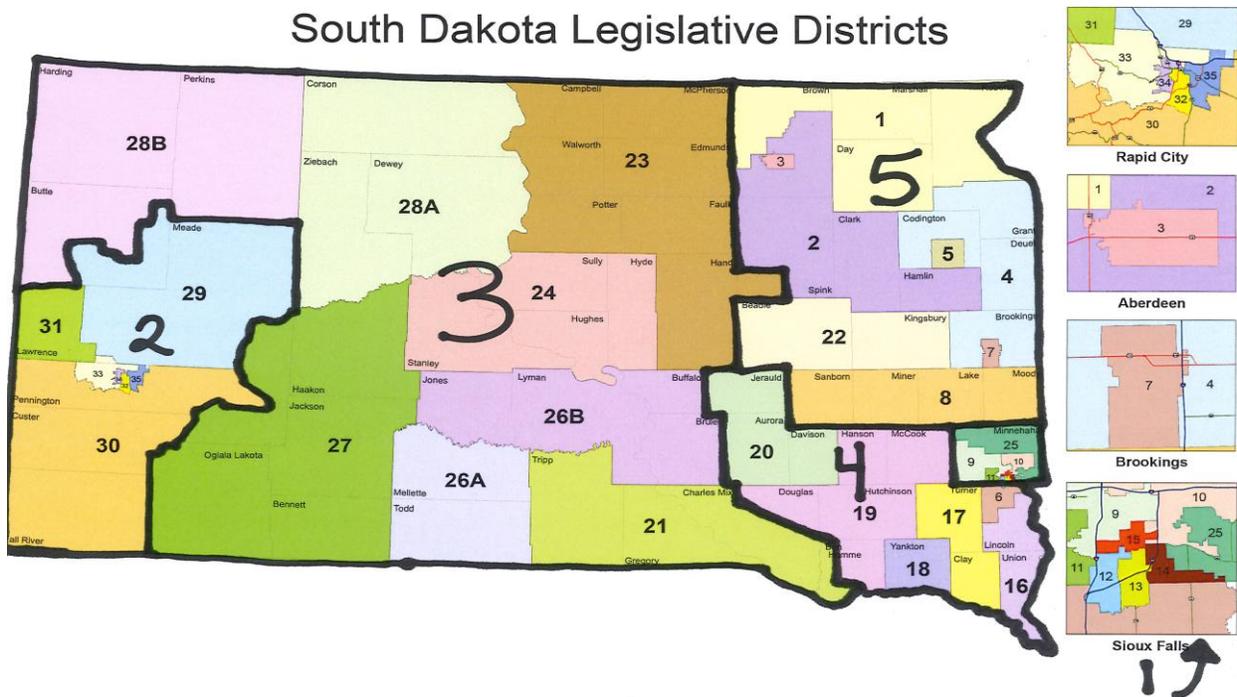
Region 2..... 35-36

Region 3.....37

Region 4.....38

Region 5.....39

South Dakota divided into five regions by legislative districts



REGION 1 FINDINGS: Encompassing the counties of Minnehaha and Lincoln.

Focus groups conducted in Sioux Falls and Brandon.

ADRD services and resources exist in Region 1. There just needs to be more of them with better access and a more competent workforce.

- When asked to name care facilities available for PWD in the community, participants listed off facilities that are either memory care exclusive or that offer a memory care unit. This speaks volumes as to what is already available in Region 1 for care facilities.
- As ADRD prevalence grows throughout the state, it will be important that additional adequate and affordable quality memory care be available in these highly populated communities.

Frustration exists in the ADRD community as to how professional care looks like today.

- There are too many barriers to accessing services and resources. The lack of knowhow amongst care professionals, the stigma, and high costs for all ADRD care types prohibit PWD and their caregivers from finding the best care possible.
- Family caregivers and PWD advocates do not see enough of a concentrated focus on what makes ADRD care different than general care or other specialized care disciplines, including how best to respond to the unique needs of PWD and honor the role and needs of family caregivers.
- Training and education for all care professionals who touch ADRD is needed. Everything from the basics—what ADRD is—to the more complex—handling behaviors, crisis response, alternative therapies. Education and re-education was called for to increase the competency of professionals working with PWD and improve upon how ADRD is managed in the health care experience.

Region 1 sees an ADRD state plan as an advocacy tool that could help PWD and caregivers get the care they need and deserve.

- ADRD is complex and requires adequate community support to improve the delivery of care. Top of mind is addressing the stigma that surrounds ADRD. With increased awareness and comfort comes better care and quality of life for PWD.
- The critical need for education and training for professional and family caregivers is a safety issue for PWD that can be brought to light through a state plan.
- A state plan can show why ADRD is important for South Dakota to address and how to most efficiently and consistently provide needed care and resources throughout the state.
- Easy access to information that helps caregivers find services for PWD and respite services for themselves, could be met if recognized in a state plan.

REGION 2 FINDINGS: Encompassing the counties of Custer, Fall River, Lawrence, Meade, and Pennington.

Focus groups conducted in Rapid City and Spearfish.

What currently exists for services and resources is inadequate throughout the region.

- Assisted living and nursing homes with memory care units exist but not on the scale that is needed to meet growing demand.
- Many assisted living, skilled nursing facilities, and home health agencies who serve PWD do not feature any memory care and are not designed to address agitation and other ADRD behaviors.
- Availability of primary and specialty physicians is low, causing long wait times for referrals, diagnosis, and treatment.
- Caregivers desire expanded access to adult day services, support groups, education, training, and continuous guidance.
- West River is limited on services and resources for higher acuity PWD. Behavioral health and crisis intervention is virtually nonexistent.
- Understaffing at care facilities compromises consistency in seeing the same care providers once a care plan is established.
- ADRD education and training is lacking for professional and family caregivers. This proves to be a barrier for family members trying to access services and resources and compromises the competency of care provided.
- When a service or resource is identified, it is often cost prohibitive, difficult to navigate within and between, and marked with limited quality assurance.

The ADRD care team includes family caregivers, family and friends, and the community. Each group should be incorporated and supported in the care of PWD.

- There is a lack of coordination, evaluation, and planning amongst ADRD services and resources.
- Caregivers lack education, support, and knowhow.
- Family members would like to be included in care plan development and implementation, at home and in a care facility.
- With increased community involvement comes increased visibility of ADRD and the potential to reduce the stigma around ADRD. Involving the likes of first responders, lawyers, financial advisors, and senior centers can improve care and increase awareness.

REGION 2 FINDINGS continued: Encompassing the counties of Custer, Fall River, Lawrence, Meade, and Pennington.

Focus groups conducted in Rapid City and Spearfish.

Improving the state of care and resources for PWD will require the attention of South Dakota lawmakers.

- The increasing prevalence of ADRD calls for action on the state level to make sure it is dealt with appropriately.
- A state plan developed from the statewide needs assessment can best articulate what the needs of PWD and their caregivers are and direct the distribution of services and resources to communities throughout the state.
- With a state plan there can be mandatory ADRD training for diagnosing physicians and other frontline care providers in South Dakota.
- Lawmakers can provide the resources and direction needed to increase the number of assisted living and nursing home beds with memory care so that PWD can access the level of care they need close to home, when they need it.
- Lawmakers can ensure a focus on resource and service development for PWD and their caregivers throughout rural West River. They can influence how best to get care to those who need it, whether it is through hosting small facilities or satellite offices in rural areas or exploring the role telemedicine could play.
- Lawmakers make it affordable and convenient to disburse.

REGION 3 FINDINGS: Encompassing the counties of Bennett, Brule, Buffalo, Butte, Campbell, Charles Mix, Corson, Dewey, Edmunds, Faulk, Gregory, Haakon, Hand, Harding, Hughes, Hyde, Jackson, Jones, Lyman, McPherson, Mellette, Oglala Lakota, Perkins, Potter, Stanley, Sully, Todd, Tripp, Walworth, and Ziebach.

Focus groups conducted in Pierre, Chamberlain, and Mobridge.

Limited services available in Region 3, especially outside of Pierre.

- Care facilities—assisted living and skilled nursing—are scarce. Participants identified two memory care facilities available in Pierre and just one memory care unit in Mobridge. Regional hospitals were noted as the main service providers for PWD.
- Caregiver support—adult day services, home health, and support groups—were reported to be limited. In a region with limited services and resources, one participant said that a support group became the biggest asset she had.
- Region 3 could benefit from having increased caregiver support services, including education and training.
- There are not enough employees or enough dollars to staff care facilities and home health agencies.

Region 3 is not connected to ADRD. ADRD knowledge, resources, and support are not present or visible.

- There is a lack of ADRD educated and trained care providers, from CNA's to physicians.
- Care providers simply do not understand ADRD. Diagnosis and symptom awareness are not adequately addressed in the health care experience.
- PWD and their care providers feel they are on their own. There is not a hub for ADRD care, some places do not even have access to services like telemedicine. There is little acceptance that ADRD is a reality. People don't know where to go or what to do for care or support.
- Participants define adequate community support as having both access to care and services and people feeling comfortable and knowledgeable enough to seek them out. Neither is a reality.

REGION 4 FINDINGS: Encompassing the counties of Aurora, Bon Homme, Clay, Davison, Douglas, Hanson, Hutchinson, Jerauld, Lincoln, McCook, Turner, Union, Yankton.

Focus groups conducted in Yankton, Vermillion, and Mitchell.

Facilities to serve PWD exist, but supply does not match demand.

- Facilities are generally understaffed.
- Staff working in these facilities are generally poorly trained.
- Most lack specialty services, such as geriatric psychiatry.
- There is rarely enough space to accommodate onsite independent/transitional living.

Caregivers drive decision making.

- The caregiver is often the first to identify a change in behavior that leads to diagnosis.
- Caregivers lack the knowledge, resources, and support network to adequately meet the needs of their loved ones with ADRD.
- An ADRD diagnosis negatively impacts a caregiver's well-being and quality of life.

Living in a rural setting is a barrier to accessing needed information and services.

- All needs associated with ADRD are compromised in a rural setting.
- Whether specific to specialty services, transportation, sufficient workforce, adequate facilities, caregiver support, stigma resistance, funding, or education/information, access to resources is significantly compromised in a rural setting.

REGION 5: Encompassing the counties of Beadle, Brookings, Brown, Clark, Codington, Day, Deuel, Grant, Hamlin, Kingsbury, Lake, Marshall, Miner, Moody, Roberts, Sanborn, Spink.

Focus groups conducted in Aberdeen, Watertown, and Brookings.

ADRD services and resources are limited by insufficient workforce numbers, high costs of providing care, and a lack of education and training.

- Memory care facilities and units in assisted living and nursing home facilities exist throughout the region but do not meet the demand.
- Caregiver support—adult day services, home health, and support groups—exists on a limited scale. An increase in caregiver support was identified as a way to improve care.
- There are not enough workers for ADRD service and resource providers to hire to adequately staff their operations. Finding qualified and certified staff is just as difficult.
- Training and education is lacking across all care provider groups—family caregivers, professional caregivers, and indirect care professionals, including police and emergency medical technicians (EMTs).
- Everything related to ADRD care, in the home or in a facility, is too expensive for facilities and families to bear without assistance. If private pay is not feasible for families, their options are significantly reduced. If reimbursement rates do not help cover costs, facilities are not incentivized to provide services or to expand service.

ADRD is not met with the proper support in Region 5.

- There is a lack of ADRD educated and trained care providers, from CNAs to physicians.
- Care providers are unskilled in diagnosing and handling ADRD, making the creation of and adherence to an effective care plan nearly impossible.
- Region 5 is made up of many small communities that either do not have access, or have inconsistent access, to specialty care providers and support services such as geriatricians and behavioral health specialists. This limited access is compounded in the surrounding rural communities.
- Participants do not believe there is adequate community support of ADRD. Resources in larger communities are not funneled to smaller communities. Any resources and support are not visible, and little is being done to do away with the stigma surrounding ADRD.

Recommendations and Strategies

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Matching Strategies to Meeting the Needs of PWD and their Caregivers

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Rationale: ADRD is associated with intensive use of services and resources over what can be a long disease course. South Dakota does not have the health care infrastructure or community supports in place to meet the needs of PWD and caregivers. When a more comprehensive and inclusive system is in place for service and resource delivery, the entire state will benefit.

Suggested strategies:

- Readdress the moratorium on nursing home beds for South Dakota. Make sure bed distribution is balanced by need and projected demand.
- Prioritize PWD's quality of life by making memory care the option for PWD, through an increase in memory care facilities and by advocating for nursing facilities to adopt memory care best practices in general population settings.
- Expand home health and community-based services to keep PWD in their homes longer to cut costs for families and the state.
- Establish a single point of entry system for PWD supported by patient navigators to ease access to information, health care services, and caregiver support services.
- Create a centralized point of information for—and access to—services and resources.
- Use technology, like telemedicine, to extend the reach of services and resources in South Dakota, better administer timely care, and reduce costs.

2. Develop funding priorities and strategies to make ADRD services and resources more affordable for facilities to provide and for families to access.

Rationale: It was determined that financial assistance and relief will be necessary to assure all South Dakotans diagnosed with ADRD receive adequate and appropriate care.

Suggested strategies:

- Establish family-caregiver funding at the state level. It is more cost efficient to keep PWD in the homes versus in a facility. This funding would be to make adult day services and in-home care more affordable and support family caregiver education and training.
- Pursue third-party reform and reimbursement at all levels, including for home health care.
- Expand Medicaid and increase reimbursement rates to improve the overall quality of care in a facility, and to help cover payroll and ADRD training costs for facility staff.

Matching Strategies to Meeting the Needs of PWD and their Caregivers

3. Execute the necessary steps on state and local levels to develop an adequately sized and skilled ADRD workforce throughout South Dakota.

Rationale: An adequately sized, educated, and trained workforce is needed to uphold South Dakota's current slate of ADRD care offerings and the industry's projected growth alongside the projected increase in ADRD prevalence in the state.

Suggested strategies:

- Professionalize the Certified Nursing Assistant (CNA) position and other formal caregiving positions to increase field numbers and show the economy values them.
- Create an ADRD certification for health care workers to attain and for home health agencies and long-term care facilities to recognize within their pay structures.
- Determine how many health care workers will be required to meet projected demand for ADRD care in South Dakota. Identify how this workforce can be cultivated within the state and how universities can play a part.
- Increase Medicaid reimbursement rate for long-term care facilities to support increasing staff pay using new standards. Increase reimbursement rates to home health agencies.
- Invest in staff. Identify leadership and professional growth opportunities.
- Attract and recruit more ADRD specialists to South Dakota and establish access channels to rural and small communities. Incentivize professionals choosing a rural work environment.

4. Prioritize the education and training of professional care providers and family caregivers to improve care quality and efficiencies.

Rationale: Standardized, affordable, and conveniently accessible education and training creates consistency in the quality of care received across care provider roles, settings, and geographic locations.

Suggested strategies:

- Educate and train all professional caregivers in residential and home care settings as well as family caregivers so they can provide and direct to the best care possible.
- Pursue the most effective mode of education and training delivery for each target audience and topic. Consider distribution through the Alzheimer's Association, workplaces, online platforms, and local events.
- Develop separate curriculums for family caregivers and professional caregivers to better equip each group to be successful in their environment.
- Standardize education and training in South Dakota and make it a requirement for all professional caregivers in the field. Support this initiative with state funding.
- Prioritize efficient and accurate diagnosis of ADRD with a built-out referral system in which care providers know what is available to their patients and from whom.

Matching Strategies to Meeting the Needs of PWD and their Caregivers

5. Reframe how ADRD is understood, seen, and cared for throughout South Dakota to reduce stigma and improve the quality of life a PWD experiences.

Rationale: When ADRD becomes a topic that people are familiar with and comfortable addressing—personally, professionally, or in the community—PWD and their caregivers are more likely to seek out and find the care they need, and the care they ultimately receive will be of higher quality than when the disease is hidden. With exposure comes attention and action.

Suggested strategies:

- Identify a champion to stand behind the cause and generate statewide attention.
- Answer the *why* for each industry to care about ADRD for the sake of business—their employees and customers.
- Develop awareness tactics. Use public service announcements, local TV and radio, radio, and the internet.
- Make sure the knowledge, resources, and support needed are visibly present to all involved with ADRD.
- Design places and host groups that welcome and cater to PWD and their caregivers, such as memory cafes, family bathrooms, and support groups.
- Create a platform for caregivers—family and professional—to share experiences and collaborate on what works best.
- Make the Alzheimer’s Association South Dakota Chapter and local councils’ efforts visible and invite the community to get involved.

Improving Support and Resources by Region

Region 1 | Opportunities to improve support and resources to PWD.

- Identify how efforts at the state level can increase the ADRD care workforce. A need for more CNAs could be met with an increase in wage through an increase in state reimbursement for care facilities or establishing a certification for ADRD skilled facilities and staff.
- Pursue third-party payer reform and reimbursement at all levels, including home care. Also consider family caregiver funding at the state level.
- Create a continuum of care for PWD.

One strategy to be successful: *“Make it a community effort. Incorporate and address the challenges of professions impacted by ADRD and then identify how they can all contribute.”*

Region 2 | Opportunities to improve support and resources to PWD.

- Increase the number of assisted living and nursing home beds with memory care so that PWD can access the level of care they need close to home, when they need it.
- Focus on resource and service development for PWD and their caregivers throughout rural West River. Consider how best to get care to those who need it, whether it is through hosting small facilities or satellite offices in rural areas or exploring the role telemedicine could play.
- Create mandatory ADRD training for diagnosing physicians and all other frontline care providers in South Dakota. Make it affordable and convenient to disburse.

One strategy to be successful: *“Mindset is important. Consider what you would like to see for our own family. What do you want available when ADRD comes to your home?”*

Region 3 | Opportunities to improve support and resources to PWD.

- Identify champions amongst community and regional leaders who can bring impact to the things they rally behind. Increasing public awareness will help decrease stigma.
- Restructure existing facilities to be better equipped in meeting the needs of PWD. Increase memory care options throughout the region.
- Establish a state-supported online platform for PWD and family caregivers to have access to physicians and specialists. Technology could help bridge distance and stigma.
- Increased reimbursement, workforce development, and the development of an ADRD skilled workforce are important in working towards meeting the needs of PWD.
- Focus on educating legislators about the need for accessible and affordable education and training.

One strategy to be successful: *“Stay engaged and follow up with all the entities around the state because things can change quickly.”*

Improving Support and Resources by Region

Region 4 | Opportunities to improve support and resources to PWD.

- Develop certification criteria for facilities and staff who work with PWD. Motivate certification achievement with financial allocation ratios directly correlated to levels of achievement. Certifications can be for education/training achievement by individuals and for achieving standards of care, providing specialty services, etc. for facilities.
- Develop a statewide public awareness campaign dedicated toward the caregiver. Emphasis symptom awareness, access to resources, defining what a caregiver is. Incorporate general awareness information to address stigmas around ADRD.
- Incentivize the start, addition or expansion of facilities in communities of fewer than 5,000 population from an economic development mindset to ensure enough access to resources.

One strategy to be successful: *“Read the study!”*

Region 5 | Opportunities to improve support and resources to PWD.

- Expand the ADRD care team to include physicians, nurses, CNA’s, pharmacists, first responders, state workers, and those in the financial and legal aid professions to cover all needs of PWD. Prioritize education and training with this group.
- Advocate for a person-centered care model of care that prioritizes PWD’s quality of life and that involves their family when appropriate.
- Host a statewide conference or educational retreat focused on ADRD for professional and family caregivers. Include presentations and learning opportunities from and for the expanded care team.
- Create an ADRD certification for care providers that employers could recognize in their pay scale.
- An ADRD certification for pharmacists, first responders, and those in the financial and legal aid professions could be promoted as a differentiator and as an ADRD-friendly partner.
- Make it possible for ADRD care facilities and agencies to thrive in small communities through increased reimbursement rates and making what is available for services widely known.

One strategy to be successful: *“Create an advisory committee that is assigned with manageable, incremental goals and held accountable to meaningful progress.”*

How the Work Group can be Successful

“How do we get everybody else to feel how we feel; see how big the issue is? That this work is not an option.”

Key issues to prioritize and work through:

- Funding on the state level through Medicaid reimbursement and expansion.
- How to increase capacity to handle higher-acuity PWD in assisted living settings.
- Respite care.
- Workforce development.
- What does a continuum of care look like?
- What does comprehensive care mean for SD?
- Accessibility and affordability of resources and services for patients and caregivers.
- Assure transportation is available.
- Better training and education for all direct care providers.
- Dollars to support an adequate and well-trained workforce.
- Reallocation of funding to support patients and caregivers.
- How will the Native American population be served?
- What a centralized, well-known spot for families and doctors to go to for answers looks like.
- Ease of access.
- How does prevention fit in?
- How to capture a person at the point of diagnosis.

Strategies to be successful:

- Bring Sanford and Avera into the conversation.
- Identify an advocate in each community.
- Invite legislators to visit all levels of care facilities.
- Get good Public Relations around it so people feel more comfortable talking about it.
- Solicit information from CNA’s, nurses, and others on the frontlines.
- Use what is working in other state plans.
- Have a Plan B for higher-acuity PWD.
- Make it a community effort. Incorporate and address the challenges of professions impacted by ADRD and then identify how they can all contribute
- Stay engaged and follow up with all the entities around the state because things can change very quickly.
- Mobilize our grassroots system. Greatest impact is achieved when churches are involved and can get the credibility by tapping into the resources that are already built.

How the Work Group can be Successful

Things to keep in mind:

- Urgency. It is not going away. Look at statistics of prevalence.
- Economic development opportunities exist.
- Scalability.
- Patient dignity and respect.
- South Dakota is rural state. What works for Sioux Falls will not work in Platte.
- Give a voice to those who cannot otherwise have their voice be heard.
- Needs to be as current as possible and continuously updated.
- Pierre recognizes the problem, but they are not exactly sure what to do with it. If there are ways that the private sector can help with that, they should be included.
- Money cannot always follow service statistics. Some things cost more in rural communities.
- Investing in adult day care and other caregiver respite services would save the state a lot of money.
- Traditional behavioral crisis resources should not be used for PWD who have behavioral problems.
- High percentage of people in nursing homes with second highest occupancy of licensed beds, which means a high waiting list.



We partner with organizations who want to improve their effectiveness and achieve high impact.

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Services and resources available for ADRD in South Dakota

Care Facilities

Assisted Living Facilities/Nursing Homes with Memory Care

- Angelhaus (Aberdeen).
- Avera Prince of Peace Retirement Community (Sioux Falls).
- Avera Sacred Heart Majestic Bluffs (Yankton).
- Bella Vista Care and Rehabilitation Center (Rapid City).
- Bethel Lutheran Home (Madison).
- Countryside Hospice Support and Memory Center (Pierre).
- Dorsett Healthcare Community by Welcov Healthcare (Spearfish).
- Dow Rummel Village (Sioux Falls).
- Edgewood Senior Living (Brookings, Mitchell, Pierre, Sioux Falls, Spearfish).
- Fairmont Grand Senior Living (Rapid City).
- Fountain Springs Healthcare Community (Rapid City).
- Freeman Nursing Home.
- The Gardens at Bethany Meadows (Brandon).
- Golden Living Center (Madison).
- Good Samaritan Society at New Underwood.
- Good Samaritan Society Sioux Falls Village and Prairie Creek (Sioux Falls).
- Grand Living at Lake Lorraine (Sioux Falls).
- The Inn on Westport (Sioux Falls).
- Jenkins Living Center (Watertown).
- Lake Norden Care and Rehab Center.
- Madison Care and Rehab Center.
- Meadows on Sycamore (Sioux Falls).
- Milbank Care and Rehab Center.
- Mobridge Care Center (used to have two ADRD units, now only one with 24 beds).
- Pioneer Memorial Nursing Home (Viborg).
- Prairie Hills Care and Rehabilitation Center (Rapid City).
- Prairie View Care Center (Woonsocket).
- Primrose (Aberdeen).
- Redfield Care and Rehab Center.
- Sanford Care Center Vermillion.
- Tieszen Memorial Home (Marion).
- Touchmark at All Saints (Sioux Falls).
- Trail Ridge Senior Living (Sioux Falls).
- The Village at Skyline Pines (Rapid City).

Skilled Nursing Facilities

- Avera Brady (Mitchell).
- Avera Maryhouse (Pierre).
- Bethany Home (Sioux Falls, Brandon).
- Bethesda Home of Aberdeen.
- Dorsett Healthcare Community by Welcov Healthcare (Spearfish).
- Golden Living Center (Pierre, Ipswich).
- Good Samaritan Center (Selby).
- Good Samaritan Society
 - At New Underwood.
 - St. Martin Village (coming 2018 to Rapid City).
- The Neighborhoods at Brookview (Brookings).
- Sanford Long-Term Care Center (Chamberlain).
- Westhills Village (Rapid City).

Assisted Living

- Avera Brady (Mitchell).
- Avera Parkwood Senior Apartments (Pierre).
- Bethany Home (Sioux Falls, Brandon).
- Countryside Living (Mitchell).
- Edgewood Senior Living (coming soon to Watertown).
- Evergreen Assisted Living (Viborg).
- Fairmont Grant Senior Living (Rapid City).
- Garden Hills Assisted Living (Spearfish). Takes residents through end of life.
- Good Samaritan Society.
 - St. Martin Village (Rapid City).
 - The Manor at Echo Ridge (Rapid City).
- Heritage Senior Living (Madison).
- Kelly's Retirement Home (Pierre).
- Lincoln Apartments (Pierre).
- Rosewood Assisted Living (Mitchell).
- Sandstone Senior Living (Spearfish).
- StoneyBrook Assisted Living (Watertown, Brookings).
- Tender Care Assisted Living (Spearfish).
- United Living Community (Brookings).
- The Village at Skyline Pines (Rapid City).
- Westhills South Assisted Living (Rapid City).

Other facilities

- AseraCare Hospice and Palliative Care (Sioux Falls).
- Compassionate Care Hospice (Sioux Falls).
- Dougherty Hospice House (Sioux Falls).

Behavioral Care

- Avera Behavioral (Sioux Falls).
- Avera Behavioral Health Senior Unit at Prince of Peace.
- Avera St. Luke's Mental Health Unit (Aberdeen).
- Human Services Center (Yankton).
- Veterans Affairs psychiatric unit.

ADRD Skilled Physicians

- Gerontologists/geriatric physicians.
- Internal medicine.

Other resources

- Alzheimer's Association (office in Sioux Falls, website, continuing education, and caregiver support).

| Caregiver Support

Adult Day Services

- Avera Sacred Heart Majestic Bluffs (Yankton).
- Ceili Cottage Adult Day Services (Sioux Falls).
- Clark Care and Rehab Center—short term and temporary stay.
- Daybreak Adult Services at Active Generations (Sioux Falls).
- Dorsett Healthcare Community by Welcov Healthcare (Spearfish).
- Freeman Nursing Home.
- Good Samaritan Society Senior Companions of South Dakota.
- Lake Norden Care and Rehab—dependent upon staff availability.
- Long Term Services and Supports Home and Community-Based Services Waiver Program through Department of Human Services.
- New Hope Adult Day Services (Madison). At capacity all the time.
- United Living Community (Brookings).
- Veterans Affairs support program.
- Western Resources for Independent Living (Rapid City).

Home Health Care

- Avera @ Home.
- Bethel Lutheran Home (Madison).
- Comfort Keepers (Sioux Falls, Brandon, Rapid City, Spearfish).
- Home Instead Senior Care (Sioux Falls, Rapid City, Mitchell, Huron).
- Interim Healthcare (Brookings, Sioux Falls).
- Long Term Services and Supports Home and Community-Based Services Waiver Program through Department of Human Services.
- Prosperous Home Health (Sioux Falls).
- Southridge Healthcare (Sioux Falls).
- SYNERGY HomeCare (Sioux Falls).
- Visiting Angels (Sioux Falls, Brookings, Aberdeen, Watertown).
- Westhills Village (Rapid City).

Caregiver support group

- Alzheimer's Association (Rapid City, Spearfish, Custer).
- Avera Brady (Mitchell).
- Bethesda Home of Aberdeen.
- James Valley Community Center (Mitchell).
- Jenkins Living Center (Watertown).
- Lake Norden Care and Rehab Center.
- Many nursing homes have caregiver support groups.
- Pioneer Memorial Nursing Home. (Viborg). 1X/month.
- Senior Center in Yankton.
- Some churches host support groups.
- Veterans Affairs.
- Westhills Village (Rapid City).

Behavioral Care

- Avera Behavioral.
- Human Services Center (HSC) Mickelson Center.
 - Provides clinical reviews for communities.
- Lewis and Clark.
- Manlove Psychiatric Group (Rapid City).

Education

- Annual education session at Freeman nursing home for staff and community.
- Dementia training provided for staff at HSC.
- Yankton Area Mental Wellness conference at Mt. Marty (often they have an ADRD speaker).

Online and in-print resources

- Alz.org
- Creating Moments of Joy by Jolene Brackey
- Common Google searches:
 - Non-pharmacological approaches.
 - Behavior reduction.
 - Everyday tips.

Other caregiver support resources

- 211 Helpline.
- Alzheimer's Association South Dakota Chapter for presentations and staff training.
- Diagnostic Center – Dr. Toni Vanderpool – in Parkston.
- Long Term Services and Supports Ombudsman Program.
- Long Term Services and Supports Caregiver Program.
- Neurologist.
- Prairie Hills Transit (Spearfish).
- Three social workers for the state in the Northern Hills.
- Urgent Care.

Community resources

- Alzheimer’s Association (office in Sioux Falls, website, continuing education, and caregiver support).
- Association of Frontal Temporal Dementia (AFTD) for information specific to FTD.
- Brookings Area Coalition on Aging.
- Health and Wellness Committee through the Aberdeen Chamber.
- YMCA in Aberdeen works with families of PWD to allow them to remain physically active.

Focus group findings from region 1 (R1)

Why is it important for South Dakota to have a state plan for ADRD?

The following were noted as important points to drive urgency for having a plan in place.

A state plan is an advocacy tool

- Vehicle to get training in place. A baseline for education and training standards.
- To provide the care PWD deserve.
- Will help PWD and their caregivers get their needs met.
- To get more money to those who need assistance to avoid the financial devastation it has on the PWD and family.
- Brings consistency and efficiency so that communities don't address the problem differently.

Not enough information

- To make finding and accessing resources easier.
- Caregiver resources need to be readily known and available.
- Lack of information on course of ADRD journey.

Not enough education or training

- Gap in training for staff to properly care for PWD, especially PWD and disabilities.
- Caregiver and family member education is important.
- Teach the general public more to help process an ADRD diagnosis sooner.

Growing aging population in SD

- Large aging population.
- Aging more than the rest of the country.

Increasing prevalence of ADRD

- A lot of people are in need of ADRD care.
- Disease is more prevalent. Try to get ahead of it.

To get the attention of lawmakers

- To show that this issue is important to SD.

"It makes sense to have a plan for treatment, care, and intervention if necessary. Can be a strain on the economy if not properly planned for."

"It's incumbent on a society to address the common good."

R1: Services and resources available for ADRD in your community?

Care Facilities

Assisted Living Facilities/Nursing Homes with Memory Care

- Avera Prince of Peace Retirement Community (Sioux Falls).
- Dow Rummel Village (Sioux Falls).
- Edgewood Senior Living (Sioux Falls).
- The Gardens at Bethany Meadows (Brandon).
- Good Samaritan Society Sioux Falls Village and Prairie Creek (Sioux Falls).
- Grand Living at Lake Lorraine (Sioux Falls).
- The Inn on Westport (Sioux Falls).
- Meadows on Sycamore (Sioux Falls).
- Touchmark at All Saints (Sioux Falls).
- Trail Ridge Senior Living (Sioux Falls).

Skilled Nursing Facilities

- Bethany Home (Sioux Falls, Brandon).

Assisted Living

- Bethany Home (Sioux Falls, Brandon).

Other facilities

- AseraCare Hospice and Palliative Care (Sioux Falls).
- Compassionate Care Hospice (Sioux Falls).
- Dougherty Hospice House (Sioux Falls).

Behavioral Care

- Avera Behavioral Health Senior Unit at Prince of Peace.
- Human Services Center (Yankton).
- Veterans Affairs psychiatric unit.
- Psychiatry care.

ADRD Skilled Physicians

- Gerontologists/geriatric physicians.
- Internal medicine.

Other resources

- Alzheimer's Association (office in Sioux Falls, website, continuing education, and caregiver support).
- Association of Frontal Temporal Dementia (AFTD) for information specific to FTD.

R1: Services and resources available for ADRD in your community?

Caregiver Support

Adult Day Services

- Daybreak Adult Services at Active Generations (Sioux Falls).
- Ceili Cottage Adult Day Services (Sioux Falls).

Home Health Care

- Comfort Keepers (Sioux Falls, Brandon).
- Home Instead Senior Care (Sioux Falls).
- Interim HealthCare of Sioux Falls.
- Prosperous Home Health (Sioux Falls).
- Southridge Healthcare (Sioux Falls).
- SYNERGY HomeCare (Sioux Falls).
- Visiting Angels (Sioux Falls).

Caregiver support group

- Many nursing homes have caregiver support groups.
- Some churches host support groups.

Other caregiver support resources

- Long Term Services and Supports through Department of Human Services.
- Parish nurses.

R1: Services or resources *missing* that would improve care?

Caregiver respite

- More support groups.
- More respite care.
- List of people—like a state network— who are willing to do respite.

Financial support and guidance

- People quit work to stay home because they don't make enough to afford in-home care.
- Fiduciary awareness. Lay groundwork upon recognition of symptoms.

Community awareness and education

- Public awareness isn't complete.
- Knowing the benefits and support system hospice care provides.

R1: Services or resources are *missing* that would improve care?

Access to services and resources

- Memory care.
 - Pre-memory care.
 - Memory care for early onset and FTD that is age and care level appropriate.
 - More memory care facilities for general ADRD population. Private-pay and Medicaid both have waiting lists. Medicaid facilities are usually full.
- Acute care
 - Facilities that can handle PWD who also have other high-acuity health problems.
 - Assisted living facilities that are licensed for higher acuity residents so that PWD don't have to transition to a nursing home before they need to.
- For PWD with behavioral problems.
- Services and resources in small towns.
- Hard to find care professionals who specialize in ADRD. No listing.

Training and education

For care professionals

- What the disease is and what they're dealing with.
- Behavioral issues and crisis response.
- Education and re-education is important to help manage staff turnover.
- Staffing is inadequate to provide ADRD care to residents with behavioral problems.
- National training.
- Employer-paid training for care workers to attain a higher-level position.
- Available alternative therapies.
- Baseline training for in-home caregivers.

Ease of access to services and resources

- Patient navigators to walk PWD and their families through what is available. Similar to what cancer patients have.
- Centralized point of access: No way to know who has beds open without making all the calls.

Workforce

- Higher wages for CNA's and home-health aides.

R1: Most significant barriers to accessing services/resources you have encountered?

Lack of ADRD education and training amongst care professionals

- Finding good quality staff and being able to pay what they're worth.
- Unprepared to handle special circumstances and situations.
- More specific training to determine diagnosis.
- Unwillingness to address issues head on.
- Early onset awareness.

Stigma

- PWD are dismissed as people who have "the old card."
- Reluctant to accept what's happening.
- Caregivers are fearful to give care over to professionals.
- People are discouraged to seek help.
 - Fear about what's to come and where the disease is headed.
 - Embarrassment.
 - Guilt.
 - Grief.

Inaccessibility of information and knowhow

- PWD and caregivers don't know where to go after diagnosis for resources.
- Don't know what's needed at different stages and when to transition.
- Caregivers need to know that others are going through the same thing.
- Need patient navigator to help along the way.

High costs associated with accessing services

- Long-term care can break the bank.
- For PWD and caregivers, many facilities don't accept Medicaid.
 - Assisted living facilities aren't required to accept Medicaid.
- Expensive for facilities to provide proper care.
 - Adequate numbers for staffing.
 - Adequate number of trained and qualified staff.
 - Not realistic to operate facility with current Medicaid reimbursement rate.
 - State regulations make it difficult for facilities to pay staff and provide quality service.

Access to services and resources.

- Struggle to find crisis services and placements for those with behavioral issues.
- Struggle to find physicians, nurse practitioners, and social workers to do home visits.

R1: How have your needs *changed* throughout your journey with the disease?

Increased need for caregiver support as disease progresses

- Support to help loved ones at home.
- Respite care.
- Self-care.
- Education.
- Support groups.

Care considerations vary through disease progression

- And vary for every person, caregiver, and family.
- Correspond to five stages of ADRD: early, middle, late, terminal, and end-of-life.
- Knowing when it's time for professional care. Usually gauged by comfort level with leaving the PWD alone.

| *"Needs for caregivers change more often than for the patient."*

R1: Is ADRD symptom awareness and management adequately addressed in the health care experience?

Consensus: No, it is not adequately addressed.

Frustration around ADRD diagnosis

- Takes several years to get a diagnosis.
- Misdiagnosis is frustrating.
- Better handled in Sioux Falls than in rural areas in SD.
- Need improved diagnostic materials.
- Difficult to find someone with expertise to diagnose. (Had three doctors and different diagnoses).

Frustration with care professionals not being able to treat ADRD appropriately

- Not acknowledging concerns of PWD and their families is disheartening.
- Need better action plans for PWD.
- Initiate education on ADRD in medical or nursing school. Care professionals need to know what they're doing and feel comfortable asking for help.

Facilities are not designed with ADRD symptoms in mind

- Plan needs to be in place in case a facility can't handle patient deterioration.
- Lack of consistency within and between facilities.

R1: What do you *value* most from an ADRD care provider or resource?

Most valuable characteristics

- Availability.
- Being current on the latest research, techniques, and drugs.
- Collaboration with other agencies.
- Compassion.
- Consistent care.
- Creativity. Willingness to be flexible and try new things.
- Dignity.
- Experience.
- Honesty, especially with prognosis.
- Respect.

Person-centered care

- Personalized care and knowing unique aspects of individual cases.
- Incorporating the PWD's preferences in things like TV shows and hobbies.
- Staff recognize patients even if the patient doesn't recognize them.
- One-on-one care and attention.
- Human touch.
- Person-centered thinking.
- Knowing what is important to PWD at the time.
- Bonds between staff and patient and staff and family.
- Do what is best for the patient, not for the facility.

Positive interaction with family

- Flexibility to visit the facility and do things that might be helpful.
- Small-town care: getting to know the person's family.
- Charting to keep family informed on daily activity.

Setting

- Inviting chaplains, pastors, schoolchildren, friends, and family to visit PWD.
- Incorporate different types of therapy, such as music, art, dance, and pet.
- Offer home evaluations.

R1: How would you define adequate community support of ADRD?

Adequate services and resources in the community

- Focus on the caregiver.
 - Respite care is available and affordable.
 - Telesupport groups.
- Facilities equipped with the security PWD need.
- Transportation present.
- Health systems organizing to meet the needs of rural communities once a state plan is established.

Efforts to do away with the stigma associated with ADRD

- Address stigma.
- Increase comfort level of friends and family to communicate with PWD better.
- Increased awareness of what the early stages look like.
- Bring about better understanding of behaviors associated with ADRD and how to properly deal with them.

Guidance

- Navigator to help establish connection with resources and manage transitions.
- Support in how to approach next steps in care.
- Help families with understanding what realistic expectations are.

The knowledge, resources, and support needed are visibly present

- Accessibility is prioritized.
- Bring ADRD experts to speak or present to families and professionals.
- Early onset support group.

Community support that is already present in the community:

- Maintaining connection to past church life.
- Daybreak at Active Generations.
- Ability to take community outings to places like the Butterfly House and local sporting events.
- Family restrooms.
- Parish nurses help keep PWD in the home.

| *“Different levels of care working together to make smooth transitions for PWD.”*

R1: Recommendations or ideas for improving the care of someone in SD living with ADRD?

“Get a state plan!” “Commitment at the state level that we (SD) will provide adequate care.”

Ensure adequate services and resources are available to PWD and their caregivers

- Revisit the moratorium on nursing home beds.
- Smaller, home-like facilities.
- Create a continuum of care for PWD.
- Services for early-onset PWD who don't fit into the average nursing home demographic.
- Acute care in assisted living facilities.
- Availability of alternative therapies. Be open-minded.
- Create a state respite care network.

Develop and distribute education and training

- Training for professional staff and family.
- Law enforcement training to better handle interaction with PWD.
- Expedite diagnosis through physician education and training.
- More standardized training for facility staff.
- Prioritize collaboration amongst facility and medical staff to be able to problem-solve on how to keep patients in their current facility.

Address the gap in workforce

- Establish certification of different levels for caregivers.
- Bring adequate wages for staff-CNA's, nurses, social workers, activity directors– through increase in state reimbursement.
- Need more CNA's and nurse aides to meet the growing need.
- Recognize signs of staff burnout and provide the necessary training and support to reduce turnover.

Develop funding priorities/strategies for SD

- More flexibility in Medicaid plan to help family caregivers.
- Pursue third-party payer reform and reimbursement at all levels, including home care.
- Consider family caregiver funding at the state level. It is cheaper to keep PWD in their homes vs. in facilities.

Increase public awareness and education

- Public awareness leading to proper recognition and care.
- Advertising campaign to raise awareness and motivate people to contact legislators.

Other priorities

- Alzheimer's Association to put together a list of needs so the community can support meeting those needs.
- Set criteria for a memory care facility.
- Use telemedicine for diagnosing ADRD in rural communities.

R1: Single most point of decline in quality of life that you, your loved ones, or patients have experienced while living with ADRD?

In terms of loss and change in ability

- Change in behavior.
- Change in personality.
- Loss of memory.
- Social isolation. Friends pull away because they don't know how to handle the disease.
- Can't read or complete a crossword puzzle.
- Loss of speech.

Transitioning through the stages

- The in-between is difficult because the PWD is in and out of knowing. It becomes easier when the PWD reaches the point of not knowing at all.
- Acting in the best interest of the PWD, even if it involves therapeutic lying or something the PWD doesn't like.
- Breaching the end-of-life discussion and considering hospice.

R1: Most important for the work group to understand and consider?

Key issues to prioritize and work through

- Funding on the state level through Medicaid reimbursement and expansion.
- How to increase acuity in assisted living.
- Respite care.
- Workforce development.
- What does a continuum of care look like?
- What does comprehensive care mean for SD?
- Anticipate challenges that the plan might encounter.

Things to keep in mind

- Urgency. It's not going away. Look at statistics of prevalence.
- Economic development opportunities exist.
- This is not a burden. It is being good citizens.
- Patient dignity and respect.
- Traditional behavioral crisis resources shouldn't be used for PWD who have behavioral problems.
- High percentage of people in nursing homes with second highest occupancy of licensed beds, which means a high waiting list.

Strategies to be successful

- Bring Sanford and Avera into the conversation.
- Make it a community effort. Incorporate and address the challenges of professions impacted by ADRD and then identify how they can all contribute.
- Identify an advocate in each community.
- Invite legislator to visit all levels of care.

| *“Setting up the right care that is available to the right person at the right time.”*

Focus group findings from region 2 (R2)

Why is it important for South Dakota to have a state plan for ADRD?

The following were noted as important points to drive urgency for having a plan in place.

To get the attention of lawmakers

- Will communicate to legislators what the needs are.
- Lawmakers need to see the needs of individuals and see the facilities.
- State plan is directional and will send people to the right places.
- We need guidelines and standards to work by.
- We don't have one and we need one.

To support the caregivers

- Effects the family member's work experience and changes productivity.
- Feelings of desperation when you have to leave patients alone.
- Will be support for the caregiver and a way to bounce ideas amongst.

Increasing prevalence of ADRD

- Dementia as an issue is getting bigger in SD and we need to deal with it.
- So many people are affected that it needs to be addressed at a state level.

Not enough information

- People are looking for information.
- Need easier access to information. No one knows where to go or who to talk to.

Not enough education or training

- We have big gaps in knowledge with both family caregivers and medical professionals.
- Convener of people with shared ideas and experiences.

Not enough or inadequate resources and care

- What is happening now is inadequate, people will be especially desperate if Medicaid gets cut.
- SD is very rural. When a loved one has ADRD, we need the whole community to help them.

R2: Services and resources available for ADRD in your community?

Care Facilities

Assisted Living Facilities/Nursing Homes with Memory Care

- Bella Vista Care and Rehabilitation Center (Rapid City).
- Dorsett Healthcare Community by Welcov Healthcare (Spearfish).
- Edgewood Vista Senior Living (Spearfish).
- Fairmont Grand Senior Living (Rapid City).
- Fountain Springs Healthcare Community (Rapid City).
- Good Samaritan Society at New Underwood.
- Prairie Hills Care and Rehabilitation Center (Rapid City).
- The Village at Skyline Pines (Rapid City).

Skilled Nursing Facilities

- Dorsett Healthcare Community by Welcov Healthcare (Spearfish).
- Good Samaritan Society
 - At New Underwood.
 - St. Martin Village (coming 2018 to Rapid City).
- Westhills Village (Rapid City).

Assisted Living

- Edgewood in Spearfish.
- Fairmont Grant Senior Living (Rapid City).
- Garden Hills Assisted Living (Spearfish). Takes residents through end of life.
- Good Samaritan Society.
 - St. Martin Village (Rapid City).
 - The Manor at Echo Ridge (Rapid City).
- Sandstone Senior Living (Spearfish).
- Tender Care Assisted Living (Spearfish).
- The Village at Skyline Pines (Rapid City).
- Westhills South Assisted Living (Rapid City).

R2: Services and resources available for ADRD in your community?

Caregiver Support

Adult Day Services

- Dorsett Healthcare Community by Welcov Healthcare (Spearfish).
- Good Samaritan Society Senior Companions of South Dakota.
- Veterans Affairs support program.
- Western Resources for Independent Living (Rapid City).

Home Health Care

- Comfort Keepers (Rapid City, Spearfish). Can keep patients until the end.
- Home Instead (Rapid City).
- Westhills Village (Rapid City).
- Nurses at home.

Caregiver support group

- Alzheimer's Association (Rapid City, Spearfish, Custer).
- Veterans Affairs.
- Westhills Village (Rapid City).

Behavioral Care

- Manlove Psychiatric Group (Rapid City).

Other resources

- Meals on Wheels.
- Prairie Hills Transit (Spearfish).
- Urgent Care.
- Three social workers for the state in the Northern Hills.
- Neurologist.

R2: Services or resources are *missing* that would improve care?

Training and education

For care professionals

- Increase education and proper training.
- Behavior management.
- Improve upon diagnostic training. Sometimes symptoms are ignored, and diagnosis therefore delayed.

For caregivers and family

- No education, didn't know anything when parent was diagnosed with Alzheimer's.
- Financial and legal preparation and planning.
 - Financial: nursing home insurance.
 - Legal: wills and advanced directives.
- Care steps.
- Questions to be addressed:
 - What should you do first? Didn't know what to do with the problem.
 - What to expect?
 - Who should you go to/Where is the support?
 - Who can you trust?
 - What will the fee be?

Access to services and resources

- There's not "one place" to go. Too many options can be confusing.
- Physician availability is low, and doctors have very high caseloads.
- Long time for referrals.
- Few physicians do outpatient care. Many doctors won't go to the nursing homes or follow their patients there.
- Increase use of telemedicine.

Access to specialty services

- Neurologist in Rapid City.
 - Has 2-4 month wait time.
 - Took almost a year to figure out diagnosis.
 - Neurologists prescribe too many antipsychotics in general.
- Lack of senior specialty services.
- Not enough Geriatricians.

R2: Services or resources are *missing* that would improve care?

Community awareness and education

- Need to talk about ADRD the same way we talk about smoking and heart disease, so people can plan better.
- People don't realize the stress caregivers are under.
- Go beyond the Walk to End Alzheimer's in distributing information to the community.
- Community outreach center for caregivers and others seeking resources.

Continuity in services and care for ADRD patients and families

- Need more memory care units. More Bella Vista like facilities.
- Communication with the Department of Aging.
- Need to look at how patients are evaluated and how that information is shared with facility staff.
- Have more continuity in questionnaires about patient likes and dislikes to keep staff from guessing.

Workforce

- Shortage of skilled employees; doctors, nurses, CNA's, etc.
- Consider more tuition reimbursement programs like the one at Westhills.

Adult day and respite services

- Adult Day Care.

Other services or resources that are missing

- Meals on Wheels in Belle Fouché.
- Community facilities to ease caregiver burden with helpful features; i.e., family bathrooms.
- No Plan B for higher acuity PWD.
 - No Crisis Intervention team when behaviors move beyond what family and professional caregivers can handle.
 - Regional West no longer admits PWD. Jail is Plan B.

R2: Most significant barriers to accessing services/resources you have encountered?

Lack of ADRD education and training amongst care professionals

- Don't know what resources are available.
- Timing of diagnosis is sometimes poor.
- Need to pick up on cues in other age groups.
- Need screening of high risk age groups.
- Poor job in knowing where the patient is at in their disease.
- Doctors present nursing homes as the only option.
- Lots of guessing is involved on the part of staff.
- Pharmacology/Medication management.
- Poor communication between staff and family.

High costs associated with accessing services

- Memory care is more expensive.
- Not every facility or doctor accepts Medicaid or Medicare.
- State hasn't expanded Medicaid.
- High cost of medications.
- Caregiving means reduced hours at work and lower income.
- Affordability impacts quality of care.

Lack of coordination, evaluation, and planning

- Transportation for services in smaller communities is lacking.
- How we take care of our elderly culturally. It is not a way of life here.
- How diagnostic tools are used.
- Evaluation and outcome measures of nursing homes are flawed.
- Don't have standards of care in place.
- Hospice rules are difficult with different progressions of the disease.
- Few know about the Department of Aging as a resource.

Lack of caregiver education, support, and knowhow.

- Not knowing where to access services.
- Figuring out what is a good resource.
- Finding quality training or classes.
- Navigating legal issues.
- Finding support through the workplace.

Living West River. Living in a rural setting.

- Rural communities are cut off from access to clinics, doctors, custodial care, and general support.
- Nothing exists West River for behavioral health. Closest is Human Services Center.

R2: Most significant barriers to accessing services/resources you have encountered?

Stigma

- Symptoms of old age instead of ADRD. “It only happens to old people.”
- Keep it hidden until there is no choice.
- People don’t understand the illness. Few try.
- Stigma affects the person with ADRD and their caregiver and family.

Other

- Regional West recently closed for PWD. They are now sent to jail.
- How to serve the Indian population.
- Money for research.
- Family issues that can negatively affect care.
 - Families that don’t visit.
 - Opinions on care from long-distance families.
 - Siblings that can’t agree on what should be done.

R2: How have your needs *changed* throughout your journey with the disease?

Care considerations vary through disease progression

- Needs change often, the type of education and guidance needed follow along.
- How to provide the best care without taking away patient rights.
- Finding better ways to address the legal hassle of keeping safe.
- Choosing the right levels of care.
- How to best get through a long journey with lots of plateaus.
- Dying with dignity issues arise.
- For professional caregivers, it eventually will be all about taking care and supporting family members.

There’s a point in disease progression where needs begin to lessen

- Loss of mobility means physical therapy is no longer needed.
- No more worries about infection or treatment.
- Less technical care is needed, more comfort care is required.

| *“After you struggle with everything else related to the disease, the disease itself seems easier.”*

R2: What do you *value* most from an ADRD care provider or resource?

Most valuable characteristics

- Patience.
- Empathy.
- Care by the golden rule.
 - Treat patients as they would want to be treated.
 - Show that they care and that they're not just there for a paycheck.
- Trust in ability, knowledge, and quality.
 - Families need to have confidence in care staff and medical care.
 - Families can't feel like they know more than the doctors.
 - Make qualifications known.

Positive interaction with family

- Include the caregiver and family in care plan development.
- Spend adequate time with the patient and family.
- Transparency and good communication and on the following topics:
 - Knowing what type of care is being provided and how.
 - Follow-up.
 - Affordability.
 - Will the money run out?
 - What Medicaid dollars might not pay in the future.

Person-centered care

- Dignity. PWD are still people.
- Independence.
- Taking patients for the entire course of the disease.
- Strive for continuity in staff to patient interaction.

Good example: Interim Health Care of Rapid City

- Could not ask for better staff.
- Staff contacted family 3-4 times/week in the beginning to adjust the care plan.
- Actual caregiver that contacts family.

R2: Is ADRD symptom awareness and management adequately addressed in the health care experience?

Consensus: No, it is not adequately addressed.

Frustration with care professionals not being able to treat ADRD appropriately

- Medication management is an issue.
- Not enough physicians are trained to cover needs.
- Some physicians miss obvious symptoms, such as urinary tract infections.
- Need more training and education to handle the different levels of care, symptoms, and complications.
- More direction in navigating next care steps.
- Lack of training leads some staff to being conned by PWD or unable to handle ADRD behaviors.

Frustration around ADRD diagnosis

- Shouldn't be hard to get a diagnosis because many things ride on it, mainly insurance issues.
- Hard to find the right doctor to diagnose and refer on to the right place if necessary.
- Long wait time for appointments.
- Upon requesting the next step in the diagnosis process, the doctor didn't move forward for a year and half

Facilities are not designed with ADRD symptoms in mind

- Need better ways to reduce agitation in health care settings.
- Buildings need to be designed for smaller groups.
- Need more consistency in providers. Staff turnover and shift changes are disturbing.

“Alzheimer’s is not linear disease. Learning how to assess individual situations and identify what options exist is very important to quality care.”

R2: How would you define adequate community support of ADRD?

Adequate services and resources in the community

- Adult day services.
- Meals on Wheels.
- Support groups.
- State social workers.
- Mental health for caregivers.
- Behavioral health for patients.
- First responder training/Public safety response team.
- Amenities and education for PWD and their caregivers.

Efforts to do away with the stigma associated with ADRD

- Offer classes open to the public. (No knowledge outside of Edgewood presentations.)
- Create awareness tactics, such as public service announcements (PSAs).
- Identify a champion or face of the disease for SD.
- Have churches and fraternal organizations talk about ADRD.

The knowledge, resources, and support needed are visibly present

- Readily accessible and continuous support and information.
 - Phone number to call for information.
 - Website.
 - Physical materials for distribution.
- Accessible education for patients, families, and all caregivers.
- Family bathrooms and other helpful amenities.

Community support that is already present in the community:

- Continued church involvement can be an opportunity.
- 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 individual likes, such as gardening.

| *“Anything and everything that supports a PWD living in the community longer.”*

R2: Recommendations or ideas for improving the care of someone in SD living with ADRD?

Ensure adequate services and resources are available to PWD and their caregivers

- Look at the moratorium on nursing home beds to see if facilities are where they need to be based on where there are large elderly populations.
- Reduce the distance a patient must move to find a facility. For example, some in Rapid City are forced to move to Huron.
- Host small facilities in rural areas.
- Increase availability of assisted living beds and nursing home beds with memory care so that patients can access the level of care they need.
- Consider designing a continuum of care for ADRD so that people can better “age in place.”
- Determine what a Plan B for PWD with behavioral problems looks like.
- Have enough respite services available for caregivers.

Develop and distribute education and training

- Advocate for more training through the Alzheimer’s Association South Dakota Chapter for everyone who will have contact with a person with ADRD.
- Education and program development for young people to foster greater community involvement and interest.
- Focus on community outreach in general.
- Mandatory primary physician ADRD specific education.
- Prioritize efficient diagnosis of ADRD among medical professionals. Cut out need for referrals if possible.

Address the gap in workforce

- Approach workforce development in medical services as a statewide issue.
- Utilize public and private colleges and universities for internships and volunteers.
- Determine how best to administer ADRD care via satellite offices.

Develop funding priorities/strategies for SD

- Push legislature to get something like a 529 plan for nursing home insurance.
- Provide an affordable nonprofit or government option for ADRD care.

R2: Single most point of decline in quality of life that you, your loved ones, or patients have experienced while living with ADRD?

Financial toll

- Financial protection of a PWD is difficult to uphold.
- Ability to make sound financial decisions decreases as the disease progresses.
- No clear or simple protocol for dealing with financial matters.
- Financial decline of the caregiver is common.

Frustration with navigating the system

- Red tape can keep the patient from the care they need.
- No clear description of steps that need to be fulfilled upon diagnosis.
- Finding the right doctor and facility to take care of a loved one.
- General lack of education for caregivers. Education could make it easier.

R2: Most important for the work group to understand and consider?

Key issues to prioritize and work through

- Accessibility and affordability of resources and services for patients and caregivers.
- Ensuring transportation is available.
- Explore what a one-stop-shop might look like.
- Better training and education for medical staff and everyone involved with care needs.

Things to keep in mind

- This is long overdue.
- What would you like to see for your family?
- Can't take away Medicaid.
- West River has different issues.

Strategies to be successful

- A live and learn situation. Learn from what has been lived.

| *“What do you want available when ADRD comes to your home?”*

Focus group findings from region 3 (R3)

Why is it important for South Dakota to have a state plan for ADRD?

The following were noted as important points to drive urgency for having a plan in place.

Not enough or inadequate resources and care

- Few resources in remote parts of the state.
- Challenging to get to basic resources in rural SD.
- Super-important that caregiver respite services and home health are part of it.
- Many don't know about all the care options, such as in-home care.
- Many patients are in nursing homes when they should be in memory care.

A state plan is an advocacy tool

- Empowers lawmakers to advocate for ADRD at a higher level.
- A white paper on what should be done for the state.
- Allow resources to be more readily available and easier to tap into.
- Could call for state assistance with facility budgets for education.

Growing aging population in SD

- Baby Boomers will need more health care as they age.
- People are living longer and will have higher needs.
- Large rural population over the age of 50.

Increasing prevalence of ADRD

- Increase in number of people who will access ADRD care.
- Dementia is being diagnosed at earlier ages.
- With growing aging population, ADRD will become a huge issue down the road if nothing is done.

Address stigma and increase awareness

- Education to dispel stigma.
- Memory care placement doesn't equal a decrease in quality of life.
- People don't want to talk about it.

Not enough education or training

- Training and education for the caregiver. So many things could be taught early on.
- Many facilities lack the educational resources needed to provide consistency in care.

Inadequate funding

- Much of ADRD care is cost prohibitive.
- Long-term care policies, even good ones, don't cover care costs.

“If we don't let this be known and put a plan in place, we are going to be floundering as a state.”

R3: Services and resources available for ADRD in your community?

Care Facilities

Assisted Living Facilities/Nursing Homes with Memory Care

- Countryside Hospice Support and Memory Center (Pierre).
- Edgewood Senior Living (Pierre).
- Mobridge Care Center (used to have two ADRD units, now only one with 24 beds).

Skilled Nursing Facilities

- Avera Maryhouse (Pierre).
- Golden Living Center (Pierre, Ipswich).
- Good Samaritan Center (Selby).
- Sanford Long-Term Care Center (Chamberlain).

Assisted and/or Independent Living

- Avera Parkwood Senior Apartments (Pierre).
- Kelly's Retirement Home (Pierre).
- Lincoln Apartments (Pierre).

Caregiver Support

Adult Day Services -> reported to be limited in this region.

Home Health Care

- Avera @ Home.

Caregiver support group -> reported to be limited in this region.

Other

- Regional hospitals.
- Avera and Sanford presence in Chamberlain and Pierre.
- Pierre Senior Center.
- First responders.
- Long-Term Services and Supports through the state.

R3: Services or resources are *missing* that would improve care?

Caregiver Respite/Support

- Adult Day Services.
- Prescription of mobility devices.
- Support groups for caregivers and families.
- Affordable home health care.
- Evenings and weekends.

Access to Specialty Services

- Openings in skilled care or placement for PWD.
- Geriatric specialist.
- Specialty services in general.
- Psychiatry.

Workforce

- Dementia certified workforce.
- Professionally treated CNA position.
- Not enough employees to staff the facilities to accommodate PWD needs.
- Not enough people to hire to staff home health care agencies.

Training and education

- For caregivers and family.
- Need mandatory training hours for staff in care facilities.
- To alleviate stigma.

Topics:

- Staff and resident safety.
- Hand-in-Hand training.

Community awareness and education

- More openness for people to discuss ADRD, seek out resources, and ask for help.

Other

- Memory care units that are separate from general population in a nursing home.
- Financial assistance to aid those on fixed incomes, living social security check to check.
- There is no way to navigate the journey. It would be nice to have someone help with the transitions of this disease.

R3: Most significant barriers to accessing services/resources you have encountered?

Lack of ADRD education and training amongst care providers

- Among professional care providers, such as CNA's, nurses, and physicians.
- Physicians don't seek out our help or expertise.
- Federal government doesn't send out enough information to facilities.
- Care facilities don't have enough money to educate staff.
- Caregivers just don't understand ADRD.
- Need something that can be put into action by caregivers.

Location. *"Out here in no man's land."*

- Must travel to Sioux Falls for certain services.
- Feel we are on our own sometimes.
- There is not a hub for specialized ADRD care near us.
- Technology; need towers to transmit.

Stigma associated with ADRD

- People are hesitant to talk about it.
- People don't want to see it. They won't volunteer or visit the nursing home.
- No one wants to admit it could happen to them. Denial.
- Caregivers don't want to accept help.

High costs associated with accessing services

- Cost barrier for all levels of support.
- Many services don't exist because there's no reimbursement for them.

Limited workforce pool

- Lack of people to hire to staff the nursing home.
- Lack of money to adequately staff a care facility.

Other

- Technology.
- Cultural barriers to accessing and serving the Native American population.
- Medicare because of all the things you must do to access care.

R3: How have your needs *changed* throughout your journey with the disease?

Care considerations vary through disease progression

- How are basic needs and emotional needs being met to support good quality of life through final stages.
- When to seek and/or intervene for diagnosis and then levels of treatment.
- Whether medication management is appropriate for the patient.
- Transition from trying to figure out what is going on to trying to know what to do next.

Maintaining connection to the PWD

- Points of familiarity.
- Products they use.
- Trying to keep a personal connection as the disease progresses to keep the trust they have in you to continue care activities, as a family member or professional caregiver.

Needing support from others

- Helpful to see caregivers and family members handling every stage.
- Realized there was a lot to learn from others.

| *“Came to need help through a support group. It became the biggest asset I had.”*

R3: Is ADRD symptom awareness and management adequately addressed in the health care experience?

Consensus: No, it is not adequately addressed.

Frustration around ADRD diagnosis

- A lot of confusion with a specific diagnosis. People don't understand that there are different types of dementia and proper treatment depends on an appropriate diagnosis.
- Need education for the different kinds of dementia and their different sets of challenges.
- Need a better way to test for ADRD early on to allow for better planning.
- Don't think the medical community understands what it looks like and how to treat.
- Lack of continuity within the neurological realm.

Don't know where to go or what to do after diagnosis.

- No acceptance or acknowledgement that ADRD is a reality.

Good example: Chamberlain Care Center.

Have received a lot of guidance on how to manage symptoms.

R3: What do you *value* most from an ADRD care provider or resource?

Most valuable characteristics and acts.

- Appropriately trained and qualified care staff.
- Trusted by PWD and caregiver.
- Demonstrated understanding of where the PWD and caregiver are at in their journey.
- Be a person the caregiver and family can talk to and get connected with information.
- Honesty in sharing information with family.
 - How difficult it can be.
 - Day to day challenges.

Person-centered care.

- Private and individualized care.
- One-on-one care is best.
- Incorporation of stimulating activities such as reading.
- Loved one looks like someone cares about their upkeep and appearance.

| *“This is their journey and you have to be there for them.”*

Setting:

- Security.
- Stable workforce.
- Clean and tidy.
- Provide community and socialization, especially for those who don’t have family that visit.
- Transparency. Families appreciate pictures and Facebook posts.

Positive interaction with family

- Care conferences with families to get feedback on interaction and behaviors.
- Family member involvement in care activities, such as doing hair.

R3: How would you define adequate community support of ADRD?

The knowledge, resources, and support needed are visibly present

- Symptom awareness.
- Access to diagnostics.
- Accessible education about long-term care.
- People feel *comfortable enough* to attend support groups.
- Senior centers need to have more access to ADRD specific information.
- ADRD hotline or message board for patients, caregivers, and families.
- Wide range of trained people.

Adequate services and resources in the community

- Adult day services.
- Multiple levels of care.
- Support groups.
- Financial advice.
- Access to transportation in smaller towns to take residents out of the facility to enjoy community life.
- Community organizations and church groups can form small alliances to offer support for caregivers and those impacted by this disease.

Efforts to do away with the stigma associated with ADRD

- Identify champions among city and community leaders. There's a lot of power and impact that can be brought to the things they rally behind.
- Focus on ADRD and make it important to the community.

Community support that is already present in the community:

- Families come out and support local ADRD efforts, but there's not enough.
- Church groups and coffee groups that welcome their friends with ADRD.

R3: Recommendations or ideas for improving the care of someone in SD living with ADRD?

Ensure adequate services and resources are available to PWD and their caregivers

- Address the moratorium on number of beds allowed in full-skilled facilities.
- Reduce the amount of travel required to access facilities in rural SD.
- Restructure facilities and improve setting and structure within facilities to meet the needs of ADRD.
- Review the prohibitive red tape and paperwork involved with respite and adult day care.
- Have nursing homes and hospice that PWD can transition to when their condition is beyond assisted living guidelines.

Develop and distribute education and training

- Mandatory training for CNA's and DON's.
- People need to be educated to accept it is a real issue. Focus on educating legislators.
- Would be nice to have one of the hospital chains “buy into” dementia to support research and education for caregivers and families.

Use technology to better administer care

- State-supported interaction tool for PWD and physicians to bridge distance and/or shame, i.e., Skype or what Avera Portal and Sanford Chart offer.
- Towers for good service in rural areas.
- Computer labs for residents in facilities.

Develop funding priorities/strategies for SD

- Improve the reimbursement rate to improve the quality of care in a facility.
- Use what other states are doing for financial management as examples.

Address the gap in workforce

- Need to be able to hire staff and pay them well.
- More people who are willing to go into this line of work/staff at all levels.
- Look at what the expected rate of increase of ADRD will be, and with that rate, determine how as a state we are going to find the people to work in these facilities.

Increase public awareness and education

- Find a champion, someone with power, to stand behind the cause.
- Create general awareness, even of those not impacted by ADRD, to take away the stigma.

Other priorities

- Have care facilities that allow family to visit.
- Adopt patient-centered care model instead of institutionalized care.

R3: Single most point of decline in quality of life that you, your loved ones, or patients have experienced while living with ADRD?

Many participants spoke about decline in quality of life in terms of loss and change...

- Loss of the ability to do things they did all their life.
- Loss of family and friends' recognition.
- Loss of relationship. Many families stop visiting in the later stages.
- Loss of dignity.
- Loss of the ability to communicate needs and express feelings to people and in turn, people don't know how to communicate with them.
- Loss of independence.
 - Can no longer drive.
 - Can no longer cook.
- Loss of identity.
 - Personal upkeep.
 - Changing behaviors.

"I often wondered what was worse, having a physical problem or having Alzheimer's. I think it's probably Alzheimer's because they lose a lot."

Emotional toll

- Isolation.
- Helplessness.
- Frustration.
- Fear.

Living with stigma

- Family and friends become too embarrassed to take the person with ADRD out.

"There is a quality of life that families don't realize is possible until they are taught. Families quit coming to see them because they don't know what to say."

R3: Most important for the work group to understand and consider?

Key issues to prioritize and work through

- Look at infrastructure for the future.
- Work on having funding in place for residents.

Things to keep in mind

- We don't have six years to wait. We need to get something written and in place in a timely manner.

Strategies to be successful.

- Stay engaged and follow up with all the entities around the state because things can change very quickly.
- Get good Public Relations around it so people feel more comfortable talking about it.

Focus group findings from region 4 (R4)

Why is it important for South Dakota to have a state plan for ADRD?

The following were noted as important points to drive urgency for having a plan in place.

Not enough or inadequate resources and care

- Connect patients and caregivers with resources that help address a variety of issues.
- Increase memory care options.
- Improve upon consistency as people progress through different levels of care.
- Reduce trouble in finding open units when care needs increase.

Not enough information

- Regarding who to talk to and ask questions to in the community (Yankton).
- What resources are available.
- What is available for ADRD training.
- What to do first, second, and third.
 - Post diagnosis is overwhelming and needs to be easier.
 - So many people are lost in the system.
 - People don't know where to go from first visit for resources and support.

Growing aging population in SD

- Aging Baby Boomer generation.
- South Dakota's large retirement community.

Increasing prevalence of ADRD

- Everyone is going to be touched by ADRD in some way.
- It's a huge problem already and it's not going away.

Not enough education or training

- About the process for caregivers and family members.
- How to deal with ADRD for care staff.

Inadequate funding

- Access to federal funding from the state to help with programs and research.
- Help to finance the kind of care ADRD patients need, such as one-on-one care.

“What can we do as providers, as neighbors, to help deal with this problem? We need to improve.”

R4: Services and resources available for ADRD in your community?

Care Facilities

Assisted Living Facilities/Nursing Homes with Memory Care

- Avera Sacred Heart Majestic Bluffs (Yankton).
- Bethel Lutheran Home (Madison).
- Edgewood Senior Living (Mitchell).
- Freeman Nursing Home.
- Golden Living Center (Madison).
- Pioneer Memorial Nursing Home (Viborg).
- Prairie View Care Center (Woonsocket).
- Sanford Care Center Vermillion
- Tieszen Memorial Home (Marion).

Skilled Nursing Facilities

- Avera Brady (Mitchell).

Assisted Living

- Avera Brady (Mitchell).
- Countryside Living (Mitchell).
- Evergreen Assisted Living (Viborg).
- Heritage Senior Living (Madison).
- Rosewood Assisted Living (Mitchell).

Caregiver Support

Adult Day Services

- Avera Sacred Heart Majestic Bluffs (Yankton).
- Freeman Nursing Home.
- New Hope Adult Day Services (Madison). At capacity all the time.

Home Health Care

- Bethel Lutheran Home (Madison).
- Home Instead.

Caregiver support group

- Alzheimer's Association.
- Avera Brady (Mitchell).
- James Valley Community Center (Mitchell).
- Pioneer Memorial Nursing Home. (Viborg). 1X/month.
- Senior Center in Yankton.

Other

- Department of Social Services respite care.
- Long Term Services and Support (LTSS) caregiver program.

R4: Services and resources available for ADRD in your community?

Behavioral Care

- Avera Behavioral.
- Human Services Center (HSC) Mickelson Center.
 - Provides clinical reviews for communities.
- Lewis and Clark.

Education

- Annual education session at Freeman nursing home for staff and community.
- Dementia training provided for staff at HSC.
- Yankton Area Mental Wellness conference at Mt. Marty (often they have an ADRD speaker).

Online and in-print resources

- Alz.org
- Creating Moments of Joy by Jolene Brackey
- Common Google searches:
 - Non-pharmacological approaches.
 - Behavior reduction.
 - Everyday tips.

Other resources

- Alzheimer's Association South Dakota Chapter.
 - Community presentations.
 - Staff training.
- Diagnostic Center – Dr. Toni Vanderpool – in Parkston.
- 211 Helpline.
- Ombudsman Program.

R4: Services or resources that are *missing* that would improve care?

Training and Education

For care professionals

- All care staff from assisted living to nursing homes.
- All professions touched by ADRD—dentists, eye doctors, chiropractors, ER.

Topics:

- Understand where the patient is at and what they can and cannot do.
- Various types of ADRD.
- CMS regulations.
- Hand-in-Hand training.

For caregivers and family

- General education.
- Behavior management.
- Personal/family finances.
- What it is and what to do.

Access to Specialty Services

- Gerontology.
- Geriatric psychiatry for when the patient becomes behaviorally challenging.
- Rural access to psychiatry care—difficult to transport patients and it's hard on them.
- Behavioral health.
- Mental health.

Community awareness and education

- What is and isn't ADRD?
- How do you properly interact with a person living with ADRD?
- How can we become more dementia-friendly?

Workforce.

- High turnover.
- Don't have the staff to offer the one-on-one care that is needed.
- Not enough people to staff home health care or care facilities.

Caregiver Respite

- Adult day care (Mitchell, Yankton, Vermillion).
- In-home respite services.

Other

- Funding
- Adequate type and number of care facilities.
- Transportation for outlying communities.
- Diagnosis: differentiate between ADRD types and give proper care.

R4: Most significant barriers to accessing services/resources you have encountered?

Living in a rural setting. “Being rural is a barrier.”

- Transportation/distance is costly to cover to get to services.
- Limited public transportation.
- Hospice doesn’t cover a 10-mile radius.
- Early-onset is especially difficult in small communities as family try to care for their loved ones with few services available.
- Private pay caregivers either 1) limit how many miles they extend their services or 2) don’t have the staff to do rural outreach.

Limited services available

- Don’t have the type and number of care facilities needed.
- Not enough facilities of varying care levels available.
- Adult day care isn’t financially feasible for small communities.
- No social services in our clinics.
- Not much available for families who want to keep their loved one at home.
- Finding consulting for clinical reviews.

Not knowing what services and resources are available in the community

- There is no comprehensive source of *what is* available.
- Finding the right level of care and how the care team can help secure that.
- Physicians aren’t aware of what is available and won’t share with families what’s appropriate, realistic, or what needs to be done.

High costs associated with accessing services

- Training.
- Caregiver supports and resources.
- Long-term care for a resident.
- High cost of facility care can be difficult for families to navigate.
- Acceptance of Medicaid vs. having to opt for private pay.
- Many people don’t utilize the care that’s available because of the cost.
- State funding does not cover costs and no direction to guide use of ADRD money.

Limited workforce pool

- Staffing needs of ADRD care are significant; one-on-one care is not realistic currently.
- Say CNA role is entry-level but it’s not; they must be on top of their game.

Other

- Eligibility requirements for facility admittance.
- Lack of education on how to properly care for PWD: care staff and family.
- No mediator between legal and financial matters; must seek a financial advisor.
- Lack of flexibility in following CMS rules for anti-psychotics.
- Regulations/square footage gets in the way of the adult day/assisted living.

R4: How have your needs *changed* throughout your journey with the disease?

Dependency on the caregiver increases, both in the home and in a facility

- Family caregivers feel so guilty about the need for respite and asking for help.
- All caregivers have to understand how the patient changes throughout the journey.
- Increased need for help and eventual dependency on executing personal care tasks.
- As the disease progresses, more help is needed.

“I know a lady at home with a finger tied to her spouse so that if he gets up, she knows.”

Care considerations vary through disease progression

- Finding the right physician, one who understands ADRD and treats appropriately.
- Pros and cons of using anti-psychotics.
- What does dignified care look like for my patient?
- Getting finances in order is important to do early on as it becomes harder as the patient gets worse.

Other

- Providers have their hands tied by federal rules which makes meeting needs harder.

R4: Single most point of decline in quality of life that you, your loved ones, or patients have experienced while living with ADRD?

Many participants spoke about decline in quality of life in terms of loss and change...

- Loss of socialization that leads to isolation for caregivers and patients.
- Loss of the ability to stay safe.
- Loss of dignity.
- Loss of self-confidence.
- Loss of independence.
- Loss of one’s voice in communicating what you need.
- Loss of who you once were or who you knew before ADRD.

“100% of your life is consumed with dealing with ADRD and the hard decisions that come with, not the person.”

Living with stigma

- When others don’t understand a patient’s actions and they look at them like that.
- They’re aware and afraid to go out.

“When someone loses their hair because they have cancer, people rally around them. But when someone with dementia goes out, people can’t “tell.” That loss of dignity is so huge, and then the stigma is attached to it. It’s incredibly isolating and people are incredibly ashamed. As families, we feel stigmatized too, it’s not just the patient.”

R4: What do you *value* most from an ADRD care provider or resource?

Most valuable characteristics

- Honesty.
- Compassion.
- Hope to help make it through, to find moments that are still meaningful.
- Availability.
 - Make sure care is there when you need it.
 - Be available to respond when a family is in crisis.
- Patience.
 - Take time to address and explain family concerns.
 - With patient care.
- Trust in ability, knowledge, and quality.
 - Be a knowledgeable provider or resource.
 - Families and caregivers will adhere to treatment suggestions better.
 - Provide good referrals to needed resources so families don't go it alone.

Person-centered care

- Patient is treated like a person.
- Show respect and dignity.
- Do what is best for the safety of the patient.
- Accept the patient for who they are and what stage they are at in the disease.
- Find staff that connects with and matches individual patients well.
- “What works well” is shared amongst all care staff on the patient's charge.
- Get to know who the patient is and their unique likes/dislikes, etc., so that the care given is what works best for that individual.

Positive interaction with family

- Get to know the patient through their family early on.
- Invite family caregiver to be part of their residential care, i.e., doing hair.

Setting

- Try for as much consistency in staffing as possible to reduce agitation.

R4: Is ADRD symptom awareness and management adequately addressed in the health care experience?

Consensus: No, it is not adequately addressed.

Frustration around ADRD diagnosis

- Difficult to get diagnosis.
- Professionals and lay people have poor symptom awareness.
 - ADRD diagnosis is never the first thought; often dismissed as depression.
 - A lot of people report getting the run around. Some are persistent, but others take the doctor's word and don't pursue concerns further.
 - Primary physicians need to know where to send people when they suspect a diagnosis.
 - Inconsistent use of diagnostic tools among primary physicians, neurologists, and psychiatrists.
- Physicians need to be straight with patients and arrange information and care sooner.
 - Prioritize patient safety.
 - Inform family of what needs to be done.

Don't know where to go or what to do after diagnosis

- Primary physicians at general appointments need to know what is available.
- Better handling of medications.

"They (physicians) say patients have a touch of dementia but they need to get the family information sooner. Nobody wanted to be the bad guy in a small town by taking away a driver's license. Nobody would take the responsibility to keep that driver safe or at least inform the family that it needed to be done. Many physicians and families are in denial."

R4: How would you define adequate community support of ADRD?

Efforts to do away with the stigma associated with ADRD

- So that people are not afraid to talk about it or to seek the resources they need.
- Feeling guilty and ashamed of a loved one's behavior is common.
- So often families with a PWD feel ostracized.
- People keep things to themselves because they don't want to show weakness, like mental health.
- Stigma is driven by fear of getting it someday. People often would rather not think about it or ask for help.
- Look to the UK's Purple Angel Project as an example of a community resource.

Making sure the knowledge, resources, and support needed are visibly present

- General education.
- ADRD educated physicians and health care professionals.
- Connection or navigation to resources post diagnosis.
- Have a variety of options available.
- Mental, physical, and spiritual support.
- Support groups; a social network.

Community support that is already present in the community:

- Caregiver program through LTSS.
- James Valley Community Center (Mitchell).
- Vermillion Senior Center.
- Opportunities exist through families.
- The ministerial associations are supportive emotionally.
- Support groups keep caregivers engaged.
- Meals on Wheels keep ADRD patients living at home engaged.
- Some home health agencies will take patients out and about.
- Some facilities try to bring in as much community life into the walls. Should do more to invite community into the facilities, i.e., local schools.

R4: Recommendations or ideas for improving the care of someone in SD living with ADRD?

Ensure adequate services and resources for PWD

- Increase availability and accessibility to adult day care.
- Adopt a patient-centered care model.
- Attract and recruit geriatric mindful practitioners and specialists to SD.
- Bring specialist outreach to rural communities, specifically neurologists, psychiatrists, and geriatricians.
- Lift the moratorium on nursing home beds because it currently limits the number of memory care beds available.
- Determine what care facilities need to offer and how they should be designed to best meet the needs of PWD and then have facilities represent those needs.

Address the gap in workforce

- Make Certified Nurse Assistant (CNA) a profession, complete with title, pay, and respect.
- Focus on statewide workforce development. Need people to train.
- Care staff turnover is high. Provide adequate training on ADRD and death and dying so that staff are more prepared for the reality of caring for PWD.

Develop funding priorities/strategies for SD

- Provide funding that's not just needs-based so that patients and families don't have to be destitute to get help.
- Increase the Medicaid reimbursement rate to allow facilities to accept more, have more training, and pay care staff more.
- Introduce a navigator position funded through the State. Look at American Cancer Society's Patient Navigator position as an example.

Develop and distribute education and training

- Utilize the Alzheimer's Association SD Chapter for care staff training.
- Provide ADRD education at all professional levels to increase awareness.

Increase public awareness and education

- Combat the stigma. Bring it out into the open from behind facility doors.

Other priorities

- Determine appropriate medication management in long term care.
- Reach out to churches and schools to see how they could play a role in ADRD care and caregiver support.

R4: Most important for the work group to understand and consider?

Key issues to prioritize and work through

- Dollars to support an adequate and well-trained workforce.
- Reallocation of funding to support patients and caregivers.
- Reimbursement rate for care services.
- Education is critical.
- How will the Native American population be served?
- What a centralized, well-known spot for families and doctors to go to for answers looks like.

Things to keep in mind

- SD is rural state. What works for Sioux Falls won't work in Platte.
- Money can't always follow your service statistics. Some things cost more in rural communities.
- Projections of disease prevalence and what SD will be facing in the years ahead.
- Investing in adult day care and other caregiver respite services would save the state a lot of money.

Strategies to be successful.

- Read the study!
- Use pieces that are working in other state plans.
- Mobilize our grassroots system. Greatest impact is achieved when churches are involved and can get the credibility by tapping into the resources that are already built.

| *“People who are aging and people with dementia need to be prioritized in South Dakota.”*

Focus group findings from region 5 (R5)

Why is it important for South Dakota to have a state plan for ADRD?

The following were noted as important points to drive urgency for having a plan in place.

A state plan is an advocacy tool

- Bring about more education and perhaps better diagnosis of ADRD.
- Proactive instead of reactive.
- Provide more support to people impacted by ADRD.
- Set standards or a template to work from.

To create a roadmap for services and resources

- Need something to guide us.
- Physicians need a roadmap outlining next steps for patients and families.
- List of what is available for resources and support. Families don't know where to go.
- So many people are lost in the system. Knowing what to do first, second, and third would really help.

Growing aging population in SD

- Big retirement community, especially with influx of senior population.
- Baby Boomers are getting older every day.
- SD has a significant aging community.

Not enough or inadequate resources and care

- Consistency in quality of care varies through the different levels.
- Travel is required for many to get to an open facility or to get the level of care needed.
- PWD are in assisted living when they should be in memory care. Without family advocating for increased care, facilities don't push them forward.

Not enough education or training

- Education for current and future caregivers.
- How to identify the different spectrums of ADRD.
- Educate about the process for caregivers and family members.

Increasing prevalence of ADRD

- Increase in the number of people with ADRD.
- Think ADRD will be diagnosed more and people will need help.
- Potential for it to reach epidemic proportions in the state.

| *"How can the state handle the care?"*

R5: Services and resources available for ADRD in your community?

Care Facilities

Assisted living facilities/nursing homes with memory care

- Angelhaus (Aberdeen).
- Edgewood Senior Living (Brookings).
- Jenkins Living Center (Watertown).
- Lake Norden Care and Rehab Center.
- Madison Care and Rehab Center.
- Milbank Care and Rehab Center.
- Prairie View Care Center (Woonsocket).
- Primrose (Aberdeen).
- Redfield Care and Rehab Center.

Skilled nursing facilities

- Bethesda Home of Aberdeen.
- The Neighborhoods at Brookview (Brookings).

Assisted living

- StoneyBrook Assisted Living (Watertown, Brookings).
- Edgewood Senior Living (coming soon to Watertown).
- United Living Community (Brookings).

Other care services and resources

- Asera Care Hospice (Sioux Falls).
- Emergency room.

Behavioral care

- Avera Behavioral (Sioux Falls).
- Avera St. Luke's Mental Health Unit (Aberdeen).
- Human Services Center Mickelson Center (Yankton).

Community resources

- Alzheimer's Association.
- Brookings Area Coalition on Aging.
- Health and Wellness Committee through the Aberdeen Chamber.
- YMCA in Aberdeen works with families of PWD to allow them to remain physically active.

R5: Services and resources available for ADRD in your community?

Caregiver Support

Adult day services

- Clark Care and Rehab Center—short term and temporary stay.
- Lake Norden Care and Rehab—dependent upon staff availability.
- New Hope Adult Day Services via Bethel Lutheran Home (Madison).
- United Living Community (Brookings).
- Long Term Services and Supports Home and Community-Based Services Waiver Program through Department of Human Services.

Home health care

- Interim Healthcare (Brookings).
- Home Instead (Huron).
- Visiting Angels (Brookings, Aberdeen, Watertown).
- Long Term Services and Supports Home and Community-Based Services Waiver Program through Department of Human Services.

Caregiver support group

- Bethesda Home of Aberdeen.
- Jenkins Living Center (Watertown).
- Lake Norden Care and Rehab Center.

Other support services and resources

- Alzheimer's Association for community presentations and staff training.
- Long Term Services and Supports Ombudsman Program.
- Long Term Services and Supports Caregiver Program.

R5: Services or resources are *missing* that would improve care?

Caregiver support

- Mental health services for caregivers.
- Active support groups in small communities.
- Most common option is nursing home placement because there is no financial support for caregivers to stay home.

Other services or resources that are missing

- Need more consistency in treatment.
- No crisis management in place to deal with behaviors or when a medication adjustment is needed. Need an alternative to ER or psychiatric care.
- A definitive point of intervention by the Department of Social Services for the safety of the PWD.

R5: Services or resources that are *missing* that would improve care?

Training and education

For direct care professionals

- Progression of the disease.
- How to appropriately approach a PWD.
- Interventions other than medical.
- Medical management.
- Signs.
- CMS regulations and Hand-in-Hand training.

For indirect care professionals

- Police and EMT: How to handle PWD in a safe manner.
- Train all professions: dentists, optometrists, chiropractors, etc.

For caregivers and family

- Education about the services and resources available.
- Patient and family education at ADRD onset.
- Progression and logistics management of the disease.
- How to appropriately approach a loved one with ADRD.
- Easy to understand overview of ADRD stages and what to expect.

Workforce

- Not enough staff.
- Not enough people to staff home health, respite, and facility care.
- Need qualified staff at all levels of care; CNA's and up.
- Consider elevating the CNA position.

Access to specialty services

- ADRD specialist, especially in terms of diagnosis and medication management.
- Psychiatric/behavioral care closer than the Human Services Center or Avera Behavioral.
- Geriatricians and Gerontologists.
- Neurology and other related specialties related to ADRD.

Adult day and respite services

- Need more adult day care.

Access to services and resources

- Varies for different ethnicities in the state.
- People don't know what is available to access.
- Due to the low Medicaid reimbursement rate, many facilities won't accept Medicaid patients because private-pay patients are reimbursed at a higher rate.

R5: Most significant barriers to accessing services/resources you have encountered?

Lack of ADRD education and training amongst care professionals

- Aren't aware of what's available.
- Don't diagnose types of ADRD, which makes it difficult to form a care plan.
- Unskilled in handling patient behaviors.
- Sometimes difficult to get medical doctors on board with care plan.
- In dealing with multiple diagnoses.
- Medical staff doesn't have time to be educated.

High costs associated with accessing services

- Costs due to longevity of the disease. On average 10-12 years.
- Everything is expensive: transportation, training, caregiver support and resources, long-term care, and medications.
- Affordability is an issue across the board.
- Not a lot of places accept Medicaid anymore. If private pay isn't an option, families must go out of town for care.
- Low reimbursement rates don't incentivize facilities to accept Medicaid patients. Can't keep doors open with how low the rates are.

Lack of ADRD services and resources

- Aren't enough facilities available.
- Not much available for families who want to keep their loved one at home.
- Only option in crisis is to send patients to Sioux Falls or the Human Services Center.
- Moratorium on nursing home beds is limiting.

Lack of coordination and planning

- Not a lot of public transportation.
- Small communities have limited access to support services.

Lack of caregiver education and knowhow.

- Caregivers do what they can with what they have, care therefore might not be the best.
- Hard to keep support groups active in small communities.
- Difficult to access or apply long-term care insurance because of 90 day wait time, lots of paperwork, and poorly written policy.

Other

- Structure of the CNA position is challenging. A lot of work for little satisfaction
- Denial on the part of family members because of fear and stigma.
- Stigma within general population. ADRD is just not commonly talked about.
- Language. Some patients revert to their native language.
- How to serve the homeless with ADRD.
- How to serve those without family assistance.

R5: How have your needs *changed* throughout your journey with the disease?

Care considerations vary through disease progression

- Finding the help, resources, and money needed to handle disease progression.
- Finding alternative treatments to medication.
- Transition from needing safety, to increased help with toileting and dressing, to complete dependence and eventual need for hospice care.
- For professional caregivers, taking care of the resident is the easier part. Family is a bigger part of where time is spent.

Maintaining connection to the PWD

- Big change when families realize their loved one's stay in a long-term care facility is permanent.
- Dealing with communication changes.

R5: Is ADRD symptom awareness and management adequately addressed in the health care experience?

Consensus: No, it is not adequately addressed.

Frustration with care professionals not being able to treat ADRD appropriately

- Need better handling of medications.
- Address end-of-life as part of the disease.
- More testing to determine stage of disease.
- How to support the caregiver.
- Knowing what resources are available.

Need to expand the ADRD care team and prioritize education for this group.

- Physicians.
- Nurses.
- Pharmacists.
- Pastors.
- First responders.
- Lawyers/legal aid.
- Department of Social Services.

R5: What do you *value* most from an ADRD care provider or resource?

Most valuable characteristics

- Patience.
- Expertise and education.
 - Ability to demonstrate and pass along.
 - From beginning to end.
- Confidence in ability to provide quality care.
- Establishing trust.
- Compassion.
- Honesty, so families can prepare the best they can for disease progression.
- Understanding of what patients are going through.
- Availability
 - Of all levels of care when they are needed.
 - When a family is in crisis.
 - To spend enough time with patients.

Positive interaction with family

- Take the time to listen, explain, and address the concerns of family members.
- Family member involvement in care activities.
- Open to family suggestions.
- Connection and communication.
- Prioritization of caregivers caring for themselves.
- Support the family. Make it known that they're not alone.

Person-centered care

- Find out what techniques work best for each patient and make sure all staff know.
- Make it about quality of life through activities, food, and the right dosage of medication.
- Incorporation of patient preferences to care plan and activities.
- Get to know PWD history through the family by asking for personal information upfront to help build a staff-patient connection.

Setting

- Safety.
- A team effort.
- Environment is important—knowing what PWD responds to.
- Make sure it's a small enough facility.
- Have the awareness to remove someone from an environment that is causing agitation.
- PWD are matched with staff who have made a connection with them. This match requires scheduling considerations.

R5: How would you define adequate community support of ADRD?

Adequate services and resources in the community

- Resources in larger communities are funneled to those in rural or smaller areas.
- Physicians willing to visit PWD at assisted living centers and nursing homes.
- Availability of Long Term Services and Supports.
- Support groups.
- Adult day and respite services. Support for people at home.
- Holistic support for patient and caregiver.
- A navigator: someone who checks in on how the patient and caregiver is doing and suggests new resources.

The knowledge, resources, and support needed are visibly present

- Folder from all primary providers outlining what resources are available.
- Physicians refer PWD to what is available in the community.
- Crisis line to deal with behaviors before emergency services are needed.
- Have the Alzheimer's Association and local councils be visible, and their efforts known.
- Network for professional caregivers to share information.
- Flexibility in support group times.

Efforts to do away with the stigma associated with ADRD

- Generate awareness so families aren't embarrassed or afraid of the diagnosis.
- Symptom awareness and management.

Community support that is already present in the community:

- Ministerial associations are emotionally supportive.
- Dependent on family to access community opportunities.

"Sometimes I feel like I can't handle the way my dad behaves, and I want someone to show me what to do. I sometimes don't know how to react in certain situations, and I just need support and understanding."

R5: Recommendations or ideas for improving the care of someone in SD living with ADRD?

Develop and distribute education and training

- Use virtual reality simulators to educate staff on what PWD are going through.
- Appoint a state expert and/or advocate on ADRD as a resource.
- Hand-in-Hand training or something equivalent readily available to all.
- Training can be no longer than 30 minutes. Facilities can only accommodate that much.
- Host a statewide conference or education retreat focused on ADRD.
- Access to support and information through a local hotline with a personal feel.
- Have all care players be aware of what is available and how to tap into it.
- Create a platform for caregivers (family and professional) to share and collaborate.

Ensure adequate services and resources are available to PWD and their caregivers

- Look at the moratorium on nursing home beds.
- More secured facilities suited for ADRD.
- More middle to end of life long-term memory care facilities.
- Increase adult day and respite services in all communities.
- Aim for a more comprehensive care system.
- Bring ADRD specialized mental health services to care facilities.
- Create a centralized resource center or a navigator position to assist caregivers.

Address the gap in workforce

- Certification for ADRD care workers for companies to employers and value.
- Examine tax structures to provide a livable wage to CNA's.
- Identify leadership and professional growth opportunities.
- Invest in facility staff. Make them feel appreciated and valued to help reduce turnover and improve quality of care.

Increase public awareness and education

- Reduce the stigma of ADRD.
- Make it known what is available and where to go for caregiver support.
- Answer the *why* for each industry/business to care about ADRD.
- Education especially for businesses, so they understand how their employees are impacted as caregivers and if customers are being taking advantage of.
- Get the word out via online resources. Use social media and other websites to educate and distribute resources.

Develop funding priorities/strategies for SD

- Establish a reimbursement rate specific to ADRD.

Other priorities

- Tap colleges for researchers, students, and education.
- Consider the opportunities that telemedicine could bring to ADRD care in SD.

R5: Single most point of decline in quality of life that you, your loved ones, or patients have experienced while living with ADRD?

Many participants spoke about decline in quality of life in terms of loss and change...

- Loss of independence to handle financial and legal matters.
- Loss of dignity.
- Loss in ability to recognize loved ones.
- Loss in ability to communicate with others.
- Changes in personality.
- Changes in behaviors, such as not eating and the subsequent weight loss.

Living with stigma

- A patient reluctant to believe they are sick and truthful about signs and symptoms.

| *“Families and friends are the ones often suffering more than the PWD.”*

R5: Most important for the work group to understand and consider?

Key issues to prioritize and work through

- Cost of education.
- Ease of access.
- Need funding to care for PWD.
- How does prevention fit in?
- How to capture a person at the point of diagnosis.

Things to keep in mind

- Urgency is necessary.
- Important for SD to participate with the rest of the nation.
- Give a voice to those who can't otherwise have their voice be heard.
- A plan on paper won't accomplish anything.
- Needs to be as current as possible and continuously updated.
- Think big.
- SD's plan should look different than other state plans because of rural population.
- Sometimes the people closest to it don't understand how to work within the confines of redirection and conflict avoidance.
- Pierre recognizes the problem, but they're not exactly sure what to do with it. If there are ways that we in the private sector can help with that, they should be included.

Strategies to be successful

- Solicit information from CNA's, nurses, and others on the frontlines.
- Use what is working in other state plans.
- Define a Plan B.
- Identify champions/advocates with a strong presence in Pierre.
- Create an advisory committee.
 - Assign manageable, realistic steps of accountability.
 - Set two goals per year.

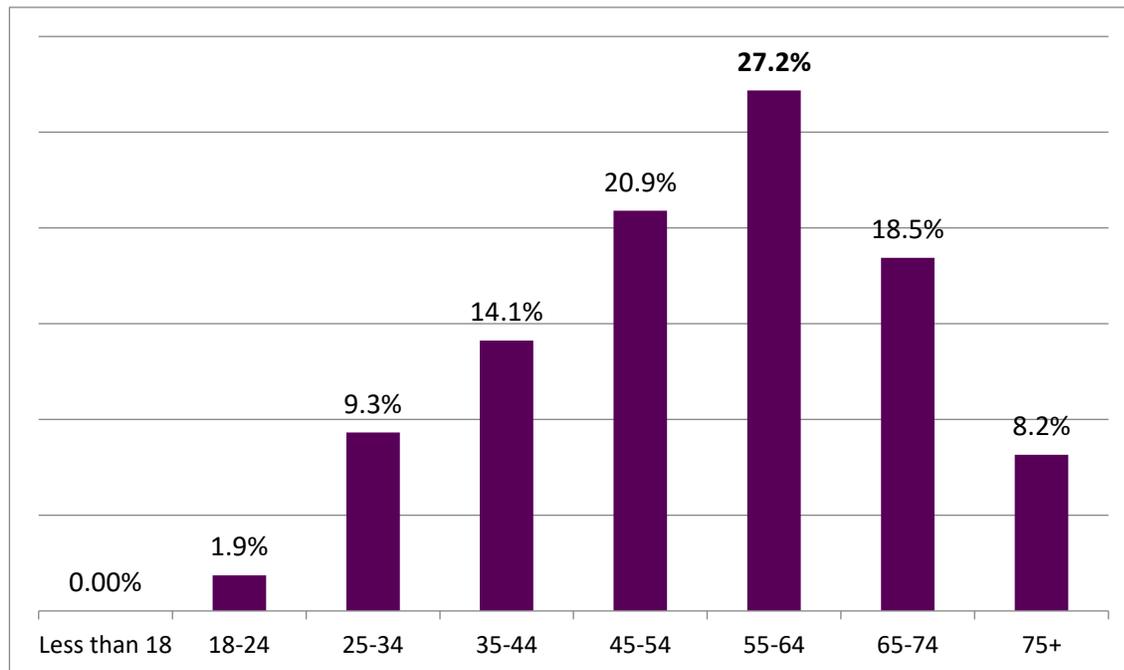
"If you can create the path of least resistance and have success, then you've put together a good plan. There are a lot of different players, but if you can find a way to manage the complexity that goes into this plan, and get it passed, that will be a success."

SD ADRD Needs Assessment Survey Results

Age Breakdown

n=1,019

Nearly 67% of survey respondents are between the ages of 45 and 74.



County Representation

n=1,004

Respondents represent 57 of South Dakota's 66 counties.

Aurora, Bennett, Buffalo, Corson, Jackson, Jerauld, Oglala Lakota, Sully, and Ziebach counties are not represented in the sample.

52 counties were represented by less than 30 respondents each, accounting for 40% of the total sample.

60% of all respondents are from 5 counties; 32.3% are from Minnehaha County.

Minnehaha	32.3%
Pennington	11.3%
Lincoln	8.1%
Brown	4.8%
Fall River	3.5%

SD ADRD Needs Assessment Survey Demographics

Sex

n=1,020

79% of respondents are female.

Female	79%
Male	21%

Ethnicity

n=1,025

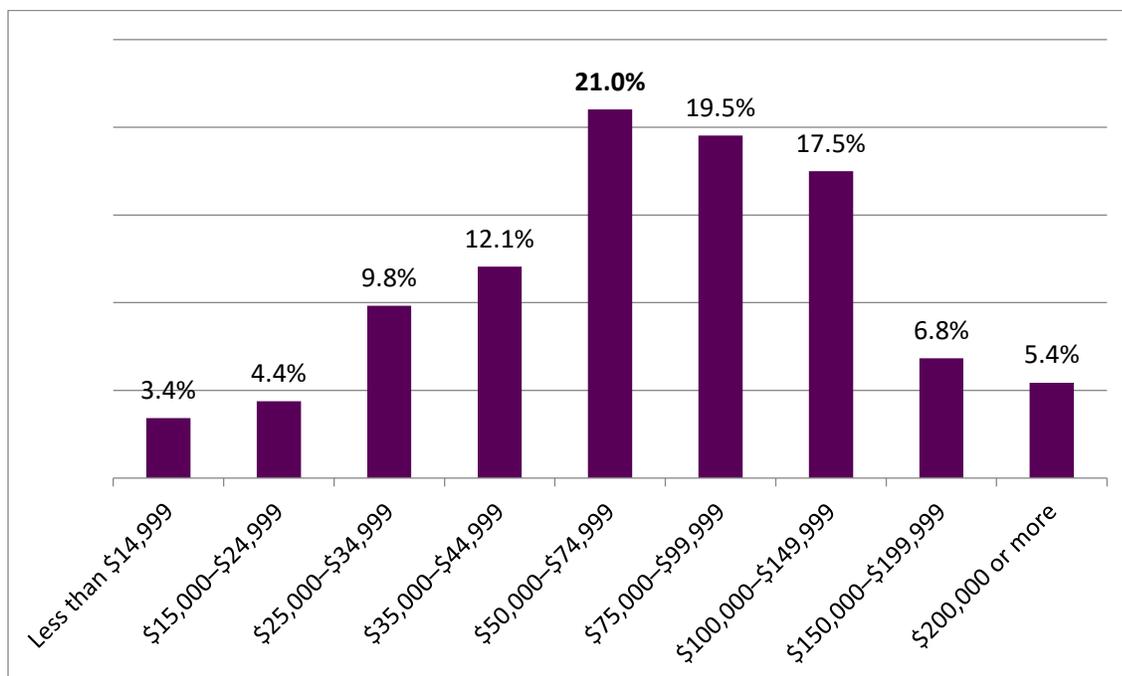
95% of respondents are White.

White	95.6%
Native American or American Indian	2.2%
Hispanic or Latino	1.0%
Asian or Pacific Islander	1.0%
Black or African American	0.2%

Household Income

n=937

58% of respondents reported household income between \$50,000 and \$149,999.



SD ADRD Needs Assessment Survey Results

Occupation, current or past

n=1,011

36.6% of respondents identified themselves with the health care profession, including health care providers, including nurses, physicians, and administrators. 13.5% are from the education field.

The other half of respondents identified with an occupation or field that did not yield 10% of the total sample. To demonstrate the breadth of occupations represented, a comprehensive list is provided here.

health care provider	media	professional services
education	customer service	private industry
social services/nonprofit	administrative	marketing
finance	IT/computer	federal
government (local/state)	insurance	engineering
agriculture	manufacturing	no occupation
business	trade industries	retired
sales	ministry	stay-at-home

Current Employment Status

n=1,000

61.9% of respondents are currently employed full-time.

Full-time	61.9%
Retired	26%
Part-time	8.8%
Not employed	3.3%

78% reported that their employment status has not been influenced by having to care for a PWD.

22% reported that caregiving did have or currently does have an influence on their employment status.

SD ADRD Needs Assessment Survey Results

Primary Connection to Alz/Dem

n=1,002

Son, daughter, or other family member of a PWD	43%
I work or have worked with people that have Alz/Dem	33.4%
Friend or acquaintance of a person with Alz/Dem	7.4%
I do not have a primary connection to Alz/Dem	7.2%
Spouse or partner of person with Alz/Dem	6.4%
Person diagnosed with Alz/Dem	2.6%

Secondary Connection to Alz/Dem *if applicable*

n=998

I know of people who had or have Alz/Dem	42.5%
Friend or acquaintance of a person with Alz/Dem	25.7%
Son, daughter, or other family member of a person with Alz/Dem	24.3%
I work or have worked with people that have Alz/Dem	18.6%
I do not have a secondary connection to Alz/Dem	11.6%
Person diagnosed with Alz/Dem	2.9%
Spouse or partner of a person with Alz/Dem	2.4%

SD ADRD Needs Assessment Survey Results

Caregiver Status

n=985

No, I have not been a caregiver	41.9%
Yes, I am a family or friend caregiver	30.9%
Yes, I am a professional caregiver	27.2%

Most helpful services or resources available to caregivers

n=366

Education: 33.6%

Very helpful	Of disease for family
Most important tool for family and staff	Recognize and appropriately communicate with, manage, and understand people with ADRD
Through employer/company	What to expect and how to respond
Hands-on experience	Knowing what is needed from the start and through progression
Keeping up to date on available resources	Caregiving techniques
Self-education	How to support the person with ADRD
Conversation with other caregivers	

Support Groups: 14.0%

Support group(s)	Through the Alzheimer's Association
From people who have been there	For early onset
To help with the stress and frustration	To talk to others

Alzheimer's Association: 10.4%

South Dakota Chapter	Website	Training materials
National office	Local office staff	Support and information
Walk to End Alzheimer's	Answer questions	Provide ideas for care

Support from Family and Friends: 8.7%

Family is the most important, helpful resource	Bring relationship, love, and motivation
Family is sometimes they only support available	Most often from siblings and unaffected parent
Help with caregiving/provide respite to primary	Supportive spouse when caring for a parent
Share experience and responsibility with family	

Respite: 8.2%

Time relief/ "time-off"	Bathing and related tasks	SD Adult Day Services
Relief from obligations	Chores/light cleaning	Daybreak Adult Day Services
Time to tend to personal needs	Bring patient suitable activities	SD DHS Caregiver program

Most helpful services or resources continued

Training: 7.9%

Training received as CNA/nurse/physician/admin	Dementia Capable Care
How to work with ADRD patients	CMS Hand in Hand
Continuing education courses for professionals	Teepa Snow DVD
At the facility level	Lanny D. Butler training course
Professional caregiver training and experience helped me in providing care to a loved one	

Care Team: 6.0%

Family doctors/Physicians	Team of caregivers	Geriatric Psychologist
Nurses	Social workers	Certified Dementia practitioners
Facility staff	Respite workers	Parish nurse

Cost Coverage/Financial Guidance: 5.2%

Financial relief for patient	Medicare	Lutheran Social Services (LSS)
Financial relief for caregivers	Medicaid	Veteran Affairs (VA)
Long term care insurance (LTC)	Affordable options for care	Kaiser Permanente
Financial reps in care facilities	State workshop on finances	

Resources/Information/Assistance: 5.2%

Research/learning on the Internet (self-taught)	Speaking with doctors and other caregivers
Reading (books, magazines, articles)	Facebook groups
Everyday experience working with ADRD	South Dakota Health Seminar
Online help to better handle symptoms	Workshops and webinars

Home Health Care: 4.6%

Social Services in-home care	Daily and on-call notice	Interim HealthCare
Help from home health agency	Set up medication	Comfort Keepers
Nursing and Hospice nursing	Help meet everyday care needs	Home Instead Senior Care

Community Support: 2.2%

Community support	Community resources	Church/Faith family
Community collaboration	Structure to address ADRD	

Organizations: 2.2%

Alzheimer's Association	Adult Services and Aging Dept.	SDHCA
Active Generations	SDAHO	AARP

Care Qualities: 1.4%

Understanding of the disease	Individualized care	Dignified/respectful care
Demonstrate expertise of ADRD	Knowing the resident's history	Work ethic and principles
Recognize effect on caregiver	Knowing likes and dislikes	

Other: legal guidance, transportation, medication management, social services.

SD ADRD Needs Assessment Survey Results

Familiarity with care and resources available for Alz/Dem in South Dakota n=988

Somewhat familiar	46.4%
Not familiar at all	30.8%
Familiar	22.9%

What participants wish they were more familiar with n=276

- 1) What is available for care and resources. (62%)
- 2) Alzheimer’s Disease and Other Dementias. (28%)
- 3) How to access available care and resources. (14.5%)

Comments for each point follow on pages 125-126.

What participants wish they were more familiar with (continued)

1) What is available for care and resources. (62%)

General comments: 22.7%

What is available in my community?	For individuals with ADRD and their families
Scope of services in community and the state	So I can make referrals
Many places don't take people with ADRD	Support systems in place for all involved
More places that work with ADRD patients	Not familiar with available resources

Specific to caregiver supports: 28.5%

Resources to help caregivers	Care for caregivers
Respite care	Information sources for caregivers
Support groups for caregivers	Education/training to be a home caregiver

Specific to care options: 21%

More information about options/availability	Care options for those not in long-term care
Better/more memory care homes	Alternatives to nursing homes
Full-time care options for ADRD patients	For individuals with disabilities
Resources for more in-home care	For individuals with behavioral symptoms
Availability of nursing home beds	

Specific to caregiver know-how: 14.5%

How to... care for the person with ADRD	Improve their quality of life
Deal with behaviors through the stages	Best assist family caregivers in healthcare
Relate and reach the person with ADRD	Prevent caregiver fatigue
Best communicate with patient/loved one	Do the right things as a caregiver
Understand what it feels like for the person	

Specific to education: 7%

Better education/training in care facilities	Programs willing to help educate or fund it
More education for family members	Trainings
Regarding the disease; to better understand	

Specific to expertise: 6.4%

Physicians with an understanding of ADRD	More specialized training for caregivers
Ability to meet with expert at diagnosis	Memory care knowledge/care facilities
Best practice for ADRD patients	Differentiation between types of dementia

What participants wish they were more familiar with (continued)

2) Alzheimer’s Disease and Other Dementias. (28%)

Onset and progression: 35.1%

How it begins; symptoms to look for	Timewise and severity
Progression of disease	Know more about the journey of the disease
Stages and symptoms	For planning purposes

Etiology: 20.8%

What causes it	Risk factors
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Prevention: 15.6%

Can you/how to prevent ADRD progression	Preventive medication/steps
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Diagnostic protocol: 13%

What are the standard diagnostic protocols	Dual diagnosis/co-occurring disorders
Better path to diagnosis confirmation	Consensus on early diagnosis

Prevalence: 11.7%

Current and projected	How common is ADRD
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Impact: 3.9%

How ADRD impacts families	Impact on caregivers	Impact on future of LTC
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3) How to access available care and resources. (14.5%)

Navigation—Who, where, and how: 57.5%

Determine when next step in care is needed	Who do you contact in SD for information
What services are available through stages	Access to services in isolated communities
Where to get support and help; steps	Regulate/rate care offered in care facilities
Direction with choosing a care facility	How to contact/work with state and other government offices
Where to seek financial, medical, counseling	For all socio-economic groups

Specific to South Dakota: 42.5%

Resources unavailable/limited in rural areas	How we compare to national numbers
Localized resources would be helpful	Where is our state plan for guidance?
How is SD helping with ADRD support	Address Medicaid reimbursement
Who do you contact in SD for information	How SD will develop professional caregivers to staff home health or facility programs
How SD will care for increase in ADRD and elderly in general on every level	

SD ADRD Needs Assessment Survey Results

Where participants go to *first* for information

n=840

Alzheimer's Association: 29.2%

SD chapter office in Sioux Falls	National website
SD chapter website	Toll free-number

Internet/Online: 26.8%

Google search	Financial resources	Support groups
Organization websites	Support groups	Local information
Look for available resources	Articles	Training

Physician/Doctor: 21%

Primary care/family physician	Local doctor	Neurologist/Neurology clinic
Health care provider	Memory care professional	Psychiatrist

State resources: 8.6%

Dept. of Social Services (DSS)	Dept. of Human Services (DHS)
Dept. of Health (DOH)	DHS LTSS

Social Network—Family, friends, colleagues, and community groups: 5.2%

Family	Community support groups
Friends	Church friends/group
Family and friends in the medical field	Colleagues/workplace

Unsure/Don't know: 5.2%

Need direction on sources	Services never advertised	No idea
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Care Facility: 3.9%

Nursing home	Senior living community	Home health care
Long-term care center	Memory center	Hospice
Assisted living facility	Care and Rehab center	

Care Worker: 2.6%

Social Worker	Parish nurse	Care facility staff
Nurse	County nurse	

Health System: 2.5%

Local health systems: Avera and Sanford	Clinic	VA
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Organizations: 2.3%

Helpline 211	SD Health Care Association
AARP	Active Generations

Other: Library/books, Medicare booklet, Health insurance provider, county.

SD ADRD Needs Assessment Survey Results

Concern about how ADRD could affect the respondent or their loved ones n=984

Scale of 1-5, 5 being very concerned

WEIGHTED AVG: 4.4

78.4% of respondents are concerned to very concerned about how ADRD could affect themselves or their loved ones.

5- Very concerned	61%
4	17.4%
3- Somewhat concerned	16.3%
2	2.1%
1- Not concerned at all	1%
I haven't thought about it	2.1%

Three most pressing needs for persons in SD impacted by Alz/Dem n=932

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%
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 persons with Alz/Dem	36.7%
7	Public awareness of the disease	10.9%

SD ADRD Needs Assessment Survey Results

Satisfaction with ADRD care and resources in SD

n=919

Scale of 1-5, 5 being very satisfied

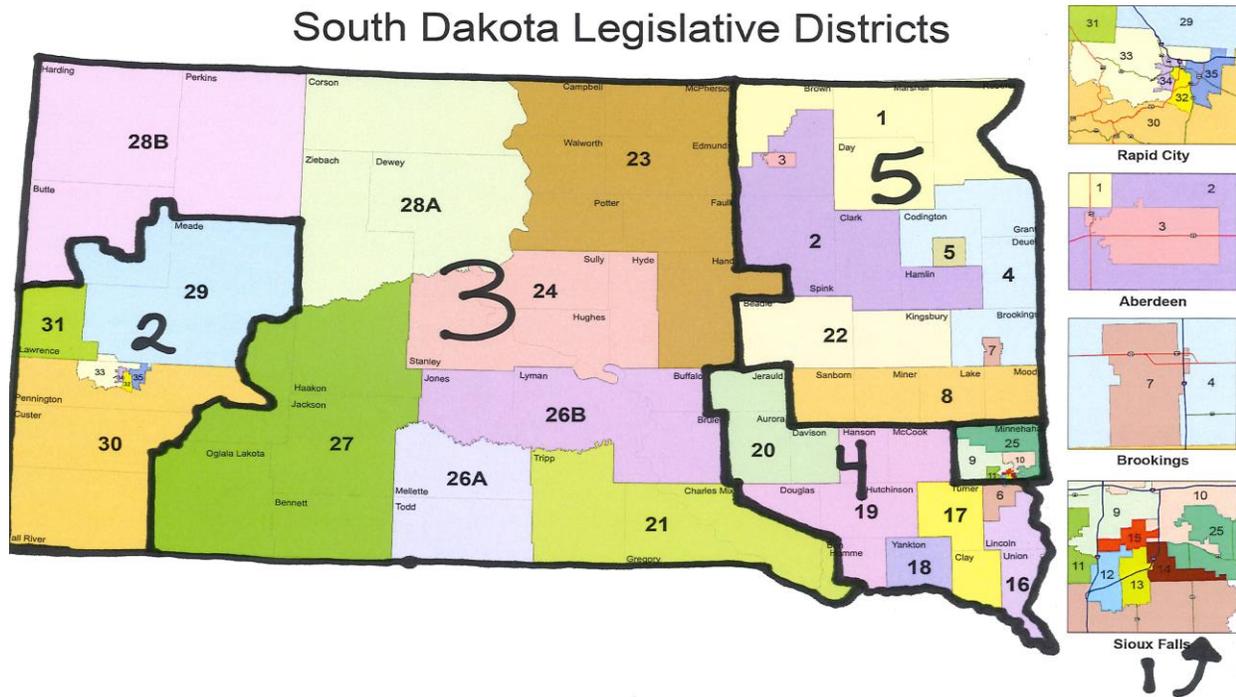
2.9	Information about and guidance in finding services and resources upon and beyond diagnosis
2.9	Quality of services and resources
2.8	Education and training of health care professionals and caregivers
2.7	Services and resource available in your area
2.7	Public awareness
2.6	Community support for family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

Quality of ADRD care in SD

Scale of 1-5, 5 being excellent

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.)

Focus Group Sites Sorted by Regions of Legislative Districts



Region 1 | 8 districts: Sioux Falls and immediate surrounding area.

- (2 focus groups) Sioux Falls
- (1) Brandon

Region 2 | 7 districts: Rapid City and the Hills area.

- (2) Rapid City
- (1) Spearfish

Region 3 | 6 districts: Pierre, Chamberlain, and Mobridge.

- (1) Pierre
- (1) Chamberlain
- (1) Mobridge

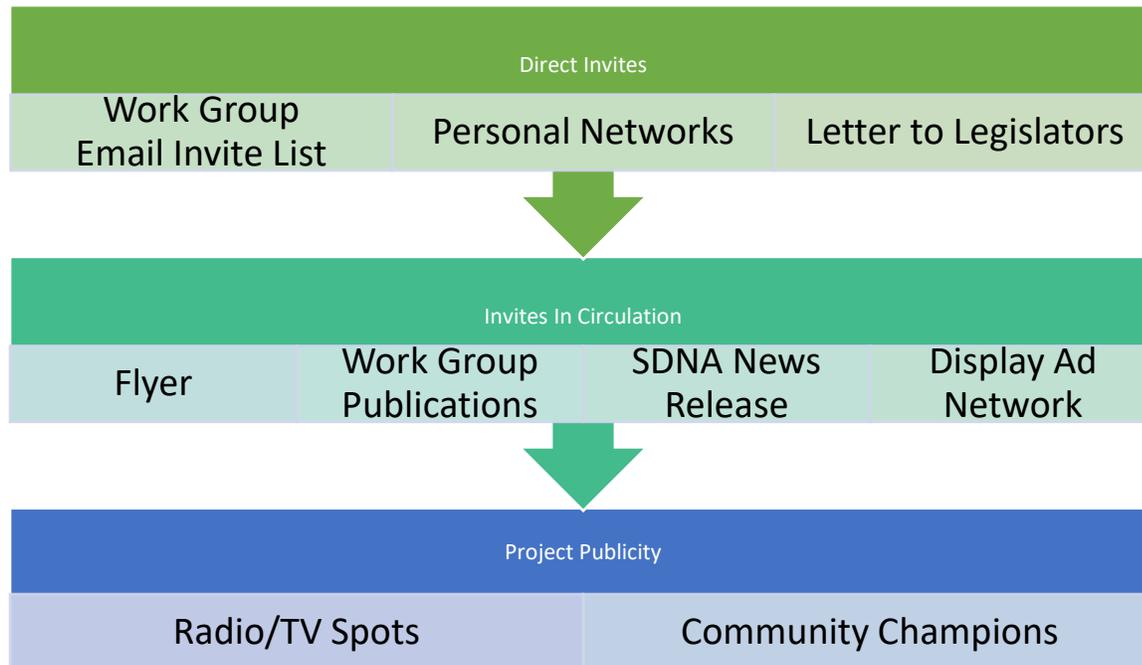
Region 4 | 6 districts: Vermillion, Yankton, and Mitchell.

- (1) Vermillion
- (1) Yankton
- (1) Mitchell

Region 5 | 8 districts: Aberdeen, Brookings, and Watertown.

- (1) Aberdeen
- (1) Brookings
- (1) Watertown

Needs Assessment Participant Outreach Strategy



Newspaper Ad (circulated in print and online)

Have you
or your
family been
impacted by
**ALZHEIMER'S/
DEMENTIA?**

WE WANT TO HEAR FROM YOU.

Your personal experience is important and will help shape South Dakota's first State Plan on Alzheimer's/ Dementia.

To hear about your experiences, we are holding focus groups in your area in September.

Contact us today to participate!
CALL - 605.339.4543 x8226
EMAIL - Imorrow@alz.org



Participant Recruitment Flyer

HAVE YOU OR YOUR FAMILY BEEN IMPACTED BY ALZHEIMER'S/DEMENTIA?

WE WANT TO HEAR FROM YOU.

Join us for a Focus Group in your community.

- Alzheimer's currently affects more than 16,000 South Dakotans and it is projected that by 2025, 20% of the state's population 65+ will be living with the disease.
- A State Plan on Alzheimer's/Dementia acts as a road map to ensure resources, policies, and personnel are in place to confront the impact of this disease.
- **Your personal experience is important and will help shape South Dakota's first State Plan.**
- South Dakota is one of only four states without a State Plan on Alzheimer's/Dementia.
- State Plans improve the quality of life for individuals and families impacted by Alzheimer's or a related dementia.



SIGN UP TO PARTICIPATE

in ONE of the following focus groups being held in your part of the state!

CHAMBERLAIN

SEPTEMBER 5 • 11:30 A.M. – 1:30 P.M.
Chamberlain Community Center,
112 N. Main St.

PIERRE

SEPTEMBER 5 • 5:15 – 7:15 P.M.
Red Rossa Hills Room
808 W. Sioux Ave.

MOBRIDGE

SEPTEMBER 6 • 11:30 A.M. – 1:30 P.M.
A.H. Brown Library
521 Main St.

SIOUX FALLS

SEPTEMBER 11 • 11:30 A.M. – 1:30 P.M.
Sioux Falls Main Library
Meeting Room B
200 N. Dakota Avenue

SEPTEMBER 12 • 5:15 – 7:15 P.M.

Caille Branch Library
4100 S. Carnegie Circle

BRANDON

SEPTEMBER 11 • 5:15 – 7:15 P.M.
Brandon Public Library
305 S. Splitrock Blvd.

YANKTON

SEPTEMBER 13 • 11:30 A.M. – 1:30 P.M.
Minerva's
1607 SD-50

VERMILLION

SEPTEMBER 13 • 3:30 – 5:30 P.M.
Vermillion City Hall
Conference Room
25 Center St.

MITCHELL

SEPTEMBER 14 • 11:30 A.M. – 1:30 P.M.
James Valley Community Center
300 W. 1st Avenue

SPEARFISH

SEPTEMBER 19 • 5:15 – 7:15 P.M.
Hudson Street Hall
222 W. Hudson St.

RAPID CITY

SEPTEMBER 20
11:30 A.M. – 1:30 P.M. • 5:15 – 7:15 P.M.
Journey Museum & Learning Center
(Library)
222 New York St.

ABERDEEN

SEPTEMBER 26 • 11:30 A.M. – 1:30 P.M.
Aberdeen Area Senior Center
1303 7th Ave. SE

WATERTOWN

SEPTEMBER 26 • 5:15 – 7:15 P.M.
Watertown Regional Library -
Community Room
160 6th St. NE

BROOKINGS

SEPTEMBER 27 • 11:30 A.M. – 1:30 P.M.
Brookings Public Library - Cooper Room A
515 3rd St.

Call 605.339.4543 x8226 or email Imorrow@alz.org to sign up today.

Refreshments will be served.

News Release

SOUTH DAKOTA ALZHEIMER'S/DEMENTIA WORK GROUP TO HOST FOCUS GROUPS

*Residents invited to discuss the development and implementation of a
South Dakota State Alzheimer's/Dementia Plan*

Sioux Falls, SD – August 7, 2017 – The impact of Alzheimer's disease and dementias is being felt across all sectors of society and has become a pivotal public health issue. According to the Alzheimer's Association's *2016 Alzheimer's Disease Facts & Figures* report, there are 16,000 people living with Alzheimer's in South Dakota and 48,000 caregivers. **South Dakota has the number one death rate from Alzheimer's in America.**

- Most people survive an average of 4 to 8 years after a diagnosis of Alzheimer's, but many can live as long as 20 years with the disease.
- Nearly 60% percent of family caregivers of people with Alzheimer's and other dementias rated their emotional stress of caregiving as high or very high.
- In 2017, the Medicaid costs of caring for South Dakotans with Alzheimer's is \$157 million.

The South Dakota Alzheimer's/Dementia Work Group is inviting residents to attend focus groups being held throughout the state during the month of September. The groups will discuss the development of a State Alzheimer's/Dementia Plan that will create the infrastructure and accountability necessary to confront the impact of Alzheimer's/dementia with a coordinated and comprehensive approach.

“South Dakota is one of just a handful of states lacking a plan to prepare for and deal with the growing epidemic of Alzheimer's and related dementias. The South Dakota Alzheimer's/Dementia Work Group is a statewide partnership of Alzheimer's advocates, each representing the interests of families and professionals,” says Leslie Morrow, State Executive Director of the Alzheimer's Association South Dakota Chapter.

Government-sanctioned Alzheimer's state plans explore the current impact of Alzheimer's disease in the state and outline what steps the state must take over the next 5 to 10 years to improve services and support for people with the disease and their families. The state planning process provides a mechanism to comprehensively consider the Alzheimer's crisis by hearing from all of the essential stakeholders: state agency officials, legislators, business leaders, the legal community, care providers, family caregivers, and people living with Alzheimer's. States then are able to collectively address the full range of Alzheimer's issues, including the availability of diagnostic services, Medicaid coverage of long-term care for people with Alzheimer's, and support services for people at all stages of the disease.

In 2012, the first-ever National Alzheimer's Plan to Address Alzheimer's Disease was enacted with the goal of preventing and effectively treating Alzheimer's by 2025. While the scientific community races toward this goal, South Dakota's comprehensive state plan will help to streamline and reduce the cost of Alzheimer's for families facing the disease now.

To learn more about the Focus Groups, please contact Leslie Morrow at 605-339-4543. For more information on Alzheimer's disease, call the Alzheimer's Association's toll-free, 24/7 Helpline at 1.800.272.3900 or visit alz.org/sd.

**South Dakota
Alzheimer's/
Dementia
Work Group**

Letter to South Dakota Legislators

Dr. James Barker

Dean Bertsch

Dr. V.R. Brandenburg

Dr. David Brechtelsbauer

Dr. Oluma Bushen

Holly Carr

Peggy Cruse

Brandy Fiala

LaVonne Gaspar

Nathan Gellhaus

Lisa Griffin

Tom Herges

Kathi Herreid

Lori Hintz

Molly Keegan

Leslie Morrow

Secretary Gloria Pearson

Edith Renner

Brad Richardson

Diana Swier

Dear LEGISLATOR,

It is projected that by 2025, 20% of South Dakotans age 65 or older will be living with Alzheimer's, a 17% increase over 2017 figures. South Dakota currently does not have an Alzheimer's/Dementia State Plan to adequately prepare for and respond to the impending increase in prevalence and the accompanying challenges of providing accessible and quality care to all who will need it.

In the spring of 2017, the South Dakota Alzheimer's/Dementia Work Group was established to develop a state plan to address the needs of individuals living with Alzheimer's and the family caregivers who support them. We are a group of health care providers, practitioners, advocacy organizations, state agency officials, and family caregivers who have voluntarily convened to oversee the process. We are in the process of conducting a thorough needs assessment to ensure the plan will be responsive to the unique needs present throughout the state.

This grassroots effort is purposed with identifying care programs and resources that are working well and the gaps that exist on statewide and community levels. The public has been invited to share their experience, expertise, and ideas through two outlets:

- South Dakota Alzheimer's/Dementia Needs Assessment Survey.
- Participation in one of the 15 focus groups being held statewide.

Focus group sites were mapped out to be inclusive of the urban and rural experience. We invite and encourage you to attend a focus group to hear what your constituents are saying about their needs related to Alzheimer's/Dementia as well as to share what your priorities are for the state plan.

To RSVP or to learn more about the project, please contact Leslie Morrow, South Dakota State Director for the Alzheimer's Association, at (605) 339-4543 ex. 8226 or lmorrow@alz.org.

Sincerely,

South Dakota Alzheimer's/Dementia Work Group