

Annual Report on Improving Alzheimer's and Related Dementia Services in South Dakota

Prepared for the House
Health and Human Services Committee



DEPARTMENT OF HUMAN SERVICES

By the South Dakota Department of Human Services
In collaboration with South Dakota Department of Health



January 13, 2025

Data

According to data from the South Dakota Department of Health (DOH):

- Alzheimer's disease was the 4th leading cause of death in 2023. Dementia was the 7th leading cause of death in 2023 for all South Dakotans.
- Alzheimer's disease was the 3rd leading cause of death from 2019-2023 for those 80+ years of age.
- 2023 was the lowest death rate in the last 10 years for Alzheimer's disease, with 398 deaths. Dementia had 255 deaths in 2023.
- SD Nursing Facilities self-reported data via an assessment tool called the Minimum Data Set (MDS). For 3rd quarter 2024, diagnosis for Neurological – Alzheimer's Disease was noted at 15.40% and Neurological – Dementia was noted at 42.24% out of 4,825 individuals in nursing facilities.

Background Information

The Department of Human Services (DHS) worked in partnership with Legislators in February of 2021 to come to an agreement on a plan to improve Alzheimer's and related dementia services in South Dakota. This agreement was made to move this important issue forward in a collaborative fashion and in lieu of legislation. Efforts already in place at the time of this agreement included:

- The Lifespan Respite Coalition is a grant funded project through the Administration for Community Living, administered by the Division of Long Term Services and Supports (LTSS) within DHS. Key priorities of the original project were to develop a respite website, complete with a database of individuals and agencies willing and available to provide respite care for caregivers of all ages.
- The Caregiver Support Program, also administered through LTSS, provides support, both financially and with information and resources. One function of this program is to serve family members or other informal caregivers, age 18 and older, who are the primary caregiver for a person of any age with Alzheimer's or related dementia.
- DHS has several staff members who have undergone specific training and are certified as Dementia Care Practitioners.
- Under the Nursing Home Innovation Grant Program in 2019, DHS funded six projects related to Dementia Care Education and Support.
- DHS provides additional reimbursement to SD nursing facilities through the Add-on Payment program to provide care for individuals supported by Medicaid with a history of challenging behaviors related to specific diagnoses, including Alzheimer's and related dementias. Services are provided in a special care unit (Sunshine Terrace) at Avera Sunset Manor in Irene and approximately 35 nursing facilities across the state, including Good

Samaritan Center in Canistota, which was the first agency to utilize this program, and supports individuals in an integrated fashion rather than in a specialized unit.

- DHS and DOH made funds available from the Civil Monetary Penalty Fund to the South Dakota Foundation for Medical Care to implement the Music and Memory Program. The Music and Memory Program is an evidenced-based program that engages residents using the therapeutic potential of music to tap into deep memories and reconnect with the world. The program was implemented in two phases beginning in 2018 and concluding in August 2022. In that time frame there was participation from 83 Nursing Homes and 500+ residents of long term care facilities who were able to utilize the program.

The Department is appreciative of the opportunity to work with stakeholders in the state to improve outcomes for people who are impacted by Alzheimer's and related dementias and their families. To this effort, DHS agreed to:

- Designate a State Alzheimer's/Dementia Coordinator within DHS. *Completed in February 2021.*
- Collaborate with the Alzheimer's Association in applying for an Alzheimer's grant from the Administration for Community Living at the next availability. *Received 2024.*
- Seek and apply for other grant opportunities related to Alzheimer's and brain health. *Ongoing.*
- Use the framework of the Alzheimer's State plan created by the Alzheimer's Association sponsored workgroup to update and establish a workplan to address Alzheimer's which ties in future grant activity requirements and state priorities. *Ongoing.*
- Continue to work with our partners, including the Alzheimer's Association, to plan for and implement strategies to address the impact of Alzheimer's in South Dakota. *Ongoing.*
- Prepare an annual report to the House Health and Human Services committee each year on the progress of the outlined efforts. *Annually in January.*

State Dementia Services Coordinator

The State Dementia Services Coordinator within LTSS allows for optimal collaboration amongst various programs and services. Specific activities of the role include:

- Provide program oversight of the Lifespan Respite grant and the Lifespan Respite Coalition which provides statewide access to respite and to respite providers.
- Provide program oversight of the National Family Caregiver Program which supports financial assistance for informal caregivers.
- Meet regularly with staff from contracted providers who administer a contract funded by LTSS to provide Caregiver education, training, and support. Some examples of trainings provided through this contract include Savvy Caregiver and Stressbusters for Caregivers.
- Research and submit applications for grants that are relevant to dementia, dementia services, lifespan respite, or caregivers.
- Serve as a hub for South Dakota Residents, professionals, and agencies to amplify and support dementia programs and services.
- Provide education and outreach for caregiver sustainability.
- Build and maintain effective working relationships with other agencies and organizations to ensure coordination and support of dementia services.
- Maintain and apply knowledge of current developments and trends by reading appropriate journals, books, and other professional literature and attending related conferences, seminars, and training.

2024 Activities

DHS is pleased to report our efforts in Alzheimer's and dementia related services in South Dakota for 2024:

- The South Dakota Long-term Care Ombudsman (SDLTCO) program was awarded a two-year grant totaling \$201,184 for dementia care education. The funding comes from the Civil Monetary Penalty Fund, administered by the DOH. In addition to previous year's activities, thirty-five individuals associated with nursing facilities, the Quality Innovation Network, and the Department of Health have completed certifications as independent consultants, trainers or coaches through Positive Approach to Care (Teepa Snow).
- Ongoing use of the Resident Experience Simulation Kits were utilized by the SDLTCO program when presenting information on Resident Rights to Nursing Facilities and Assisted Living Centers.
- Recruitment of volunteer Ombudsman continues, which will help expand the presence and assistance of an Ombudsman in nursing facilities, assisted living settings and community living homes. An Ombudsman visits with residents, advocates for resident rights, and conducts ongoing education, which includes training on Alzheimer's and related dementias.
- SDLTCO team received training and certification in essentiALZ, a certification course on current evidenced-based, person-centered practices to care for individuals living with dementia.
- A new contract was signed with Helpline to replace the resource directory through Dakota at Home. Helpline will ensure the resource directory records are reviewed and updated and provides printable search results based on one or more selected demographic regions, service types, etc. Additionally, Helpline will ensure it is user-friendly and accessible. Respite & Caregiver Services is one category as well as Dementia as a sub-category within the resource directory.
- Ongoing promotion of Trualta, an on-demand caregiver education and wellness platform, to help support consumers and family caregivers to manage care at home by easing caregiver burden. This is funded by the Lifespan Respite grant and National Family Caregiver Support funds.
- Added virtual support groups to Trualta contract to meet the needs of consumers and family caregivers across the state, especially in rural areas where access to an in-person support group may not be available.
- The Alzheimer's Disease Prevention Initiative (ADPI) is a grant funded through the Administration for Community Living (ACL). DHS applied for the cooperative agreement totaling \$1,059,973 over three years. The grant funds will be used to provide essential

support to individuals living with dementia and their family caregivers through direct support services, increasing awareness and reducing stigma by engaging communities and helping individuals living with dementia remain independent and safe in their communities. The initiative will adopt a multi-phased approach with two pilot programs in Aberdeen and Belle Fourche over the three year period.

- Continued financial support of care for individuals supported by Medicaid through various DHS home and community based services as well as through the extraordinary care/add-on payment process for nursing facilities for residents with challenging behaviors, including those impacted by a dementia diagnosis.
- Implementation of the adjusted mapping for the rate tiers for reimbursement of Medicaid supported Assisted Living settings as well as Community Living Homes and the Structured Family Caregiving program to ensure reimbursement through evaluating all of the needs of a participant, including those impacted by cognitive impairment.
- Contracted with South Dakota Foundation for Medical Care to facilitate Dementia Dialogues across the state. Dementia Dialogues is a nationally registered and evidence-informed intervention program designed to educate community members and caregivers for persons who exhibit signs and symptoms of Alzheimer's disease and related dementias. Training sessions have been conducted for emergency medical services, community health workers, local chambers of commerce, etc.
- DHS monitored and provided reimbursement for the adult day grant projects with appropriation during the 2023 legislative session developed to expand adult day services for those living with dementia or symptoms in alignment with dementia. These projects are expected to significantly expand the capacity for adult day services throughout the state with anticipated completion ranging from 2025 to fall 2026.
- Expanded contract with Active Generations, as a part of the caregiver outreach program, to conduct a statewide caregiver support services public service campaign to facilitate support groups and memory cafés (welcoming places for individuals with Alzheimer's, dementia, and mild cognitive impairment) across the state, which focuses on fifteen rural, underserved communities and rural, faith-based communities.
- Collaborated with vendor to develop Year 2 awareness and marketing plan, including local networking, to reach our target audience of older adults, adults with disabilities and caregivers, which includes those impacted by dementia.
- Provided direct support services through DHS contracted providers, or reimbursement for services, to individuals and their caregivers across South Dakota for respite, adult day, adult companion, homemaker, personal care, nursing, and/or emergency response system equipment and monitoring.

- Through an appropriation during the 2024 legislative session with Senate Bill 80, DHS awarded \$2 million in technology equipment grants to 73 long term care providers. Some of the technology equipment that was awarded is anticipated to benefit those impacted by dementia.
- Developed content for a new Dementia Road Map resource to help those impacted by dementia navigate the journey as well as established a partnership with DOH on this work. Anticipated release to share with individuals, families, caregivers, physicians, etc. is in 2025.
- Collaborated with the Department of Health BOLD (Building Our Largest Dementia) public health infrastructure grant to expand and improve the response to Alzheimer's disease and related dementias (ADRD).
- Participated on the SD Healthy Brain Coalition, sharing resources, identifying current needs, and working together to develop a statewide strategic plan to address ADRD. The plan will include strategies to address dementia risk reduction; early detection and diagnosis; prevention of avoidable hospitalizations; and supporting dementia caregiving.
- Conducted a State Plan on Aging Needs Assessment focused on older adults and their caregivers.

Building Our Largest Dementia Public Health Infrastructure grant

The Department of Health (DOH) received a federal Center for Disease Control BOLD public health infrastructure grant for \$1.25 million to aid in the department's development and implementation of a prevention program centered around ADRD. This is the first time South Dakota has received a grant of this kind. The department will use best practices and optimize evidence-based strategies to create a bold and sustainable public health approach in addressing this ever-growing issue in South Dakota.

The DOH will collaborate with the Alzheimer's Association South Dakota Chapter; SDSU Extension Better Choices, Better Health SD program; other state agencies; and healthcare industry partners to establish a coalition to reduce the burden of ADRD through a prevention-focused public health approach aligned with the Center for Disease Control's Healthy Brain Initiative. The coalition will assist the department with improving public health infrastructure and increasing capacity in the field, as well as increasing awareness of the disease and improving access to resources for individuals and caregivers affected by ADRD.

Next Steps

In the Division of Long Term Services and Supports, our team focuses on enhancing and promoting the quality of life for older adults, adults with disabilities, and their caregivers, at home and in the community. We consider a variety of factors in our strategic planning to serve older adults, adults with disabilities, and their caregivers, including those impacted by Alzheimer's and dementia. As such, we anticipate the following activities or focuses in the future related specifically to Alzheimer's and dementia:

- Ongoing use of the Dementia Simulation Kits and dementia training through the Ombudsman program, specifically in nursing facilities, assisted living settings and community living homes, to help gain an awareness of what a person living with dementia may experience.
- Ongoing recruitment of volunteer long term care Ombudsman to assist families and residents living in nursing facilities, assisted living settings and community living homes to advocate for their rights as well as ongoing education around Alzheimer's and dementia.
- Ongoing awareness and marketing campaign, including local networking, to reach our target audience of older adults, adults with disabilities and caregivers, which includes those impacted by dementia.
- Continue to increase respite caregivers, both formal and informal.
- Ongoing promotion of Trualta for on-demand caregiver education and wellness options, including virtual support groups.
- Ongoing monitoring of the adult day grant to ensure project completion and expansion of adult day services for those living with dementia or symptoms in alignment with dementia.
- Ongoing monitoring of the technology equipment grants to ensure project completion.
- ADPI cooperative agreement activities, including piloting a dementia-friendly community in Aberdeen
- Exploring additional avenues to meet caregiver needs.
- Ongoing training of Dementia Dialogues.
- Ongoing training for LTSS team, specific to Dementia.

- Completion of the Dementia Road Map resource for those impacted by dementia, and develop a distribution plan.
- Collaboration between Department of Human Services and Department of Health, including participation on the Healthy Brain coalition to finalize the five-year strategic plan for South Dakota.
- Completion of the State Plan on Aging and submission to the Administration on Community Living for approval.

2023 Activities

A highlight of some of the efforts from 2023 are noted below:

- The South Dakota Long-term care Ombudsman (SDLTCO) program was awarded a two-year grant totaling \$201,184 for dementia care education. The funding comes from the Civil Monetary Penalty Fund, administered by the DOH. In addition to 2022 activities, twenty-three individuals associated with nursing facilities, the Quality Innovation Network, and the Department of Health have completed certifications as independent consultants, trainers or coaches through Positive Approach to Care (Teepa Snow). Every individual, as well as each nursing home, who signed up to become certified also received a box of resources to use when providing their educational sessions. Due to the volume of individuals taking certification courses and champion courses, there will be individuals taking those courses yet in 2024.
- Resident Experience Simulation Kits were utilized by the SDLTCO program when presenting information on Resident Rights to Nursing Facilities and Assisted Living Centers. These simulation kits provide the opportunity for facility staff to experience life through the viewpoint of residents. The training utilizes tools that simulate various disabilities experienced by those living with dementia including, low vision, impaired hearing, decreased mobility, and auditory hallucinations, etc.
- A volunteer Ombudsman program was developed that will expand the presence and assistance of an Ombudsman in nursing facilities, assisted living settings and community living homes. An Ombudsman visits with residents, advocates for resident rights, and conducts ongoing education, which includes training on Alzheimer's and related dementias. Recruitment of volunteers began in September 2023 and will be ongoing.
- The Lifespan Respite website was brought under the new DHS website for easier access and to lend credibility to the information it provided. A benefit of this will be consumers will have access to other resources on the DHS website that might be helpful.
- Contract for Trualta, an on-demand caregiver education and wellness platform, was completed using grant funding. DHS will promote this free service to help support consumers and family caregivers to manage care at home by easing caregiver burden. Promotion activities were conducted to bring awareness to Trualta.
 - The library in Trualta covers a broad spectrum of conditions including Alzheimer's and dementia, brain health, heart health, diabetes care.
 - This is especially beneficial for all caregivers as it is on-demand and participants can self-register for access to the platform.
 - Trualta has partnered with Positive Approach to Care - Teepa Snow for dementia specific modules. Teepa Snow is a nationally recognized expert in dementia care

and services.

- The Dementia Services Coordinator will be able to add DHS/LTSS specific content and maintain links and calendars for South Dakota specific events.
- The State Dementia Services Coordinator has coordinated with the policy director at the SD Chapter Alzheimer's Association.
- The Alzheimer's Disease Prevention Initiative is a grant funded through the Administration for Community Living. DHS has applied for this grant; however, has not been awarded. A grant proposal will be submitted at a future grant opportunity; however, aspects that were a part of the application for this grant have been pursued through other funding opportunities to advance dementia services, including dementia dialogues, partnerships with local stakeholders, and partnerships with faith-based communities for respite.
- An application and proposal were submitted for enhancement of the current Lifespan Respite grant. DHS was awarded the grant totaling \$220,898. A portion of the awarded funds will be used to create support groups and memory cafes, which are welcoming places for individuals with Alzheimer's, dementia, and mild cognitive impairment.
- Continued financial support of care for individuals supported by Medicaid through our various home and community based services as well as through the extraordinary care/add-on payment process for nursing facilities for residents with challenging behaviors, including those influenced by dementia diagnoses.
- Rate methodology review was conducted that included an analysis of the rate tiers for Medicaid supported Assisted Living settings as well as community living homes and structured family caregiving program to ensure individuals needing additional time are in the appropriate tier, including those impacted with cognitive impairment.
- Implementation of the new nursing facility methodology, which includes PDPM (Patient Driven Payment Model) through the Centers for Medicare and Medicaid Services (CMS), which reimburses nursing facilities based on an assessment of care needs.
- Implementation of the new Adult Day Services rates appropriated during the 2023 legislative session.
- A request for proposal (RFP) was issued to facilitate Dementia Dialogues across the state. Dementia Dialogues is a nationally registered and evidence-informed intervention program designed to educate community members and caregivers for persons who exhibit signs and symptoms of Alzheimer's disease and related dementias. Anticipated award date is Spring 2024.
- The Division of Long Term Services and Supports held training for all employees on dementia. The training was facilitated by Teepa Snow, a nationally recognized expert in

dementia care and services.

- The Dakota at Home intake assessment was updated to include additional questions to assess for cognitive impairment. Depending on the responses, Dakota at Home may recommend consulting their physician.
- Within the Division of Long Term Services and Supports, Case Management Specialists are the direct connection to consumers as they visit consumers in their home to conduct an assessment to determine their needs. Each region has a Case Management Specialist who has received training specific to Memory Care and Dementia for Case Managers. The additional training is beneficial to each region across the state to serve as a resource for all employees.
- DHS developed and published a grant application for the \$2M appropriated in the 2023 legislative session to expand adult day services for those living with dementia or symptoms in alignment with dementia. After thorough review, funds were awarded to four organizations in the state. These projects are expected to significantly expand the capacity for adult day services throughout the state.
- DHS has focused communication to Assisted Living providers informing them of the opportunities to contract with DHS for adult day services. These communications are expected to be ongoing.
- DHS issued an RFP to solicit proposals for professional marketing services to reach our target audience of older adults, adults with disabilities and caregivers, which includes those impacted by dementia. A vendor was selected and has created a cohesive marketing plan and strategy showcasing the individual programs and services DHS offers. A marketing and awareness campaign was launched in November 2023.
- Submitted a letter of support for the Department of Health application for the BOLD (Building Our Largest Dementia) infrastructure grant for public health programs to address Alzheimer's disease and related dementias.

2022 Activities

A highlight of some of the efforts from 2022 are noted below:

- DHS/LTSS was awarded \$420,931.55 for a five-year grant cycle for Lifespan Respite, which was initially awarded in 2021. DHS/LTSS will continue to receive funding through June 2026. The SD Lifespan Respite Website was created with the hope to have a “one-stop” location where South Dakotans could locate both individual and agency respite providers based on location.
- The Dementia Services Coordinator attended the first annual Dementia Service Coordinator Summit in Washington, DC along with local SD Chapter Alzheimer’s Association staff, which allowed for networking with other states and the Alzheimer’s Association, in addition to learning about grant opportunities.
- Researched opportunities with Trualta for on-demand caregiver education and wellness options.
- The State Dementia Services Coordinator took over facilitation of the Statewide Dementia Coalition. This group meets quarterly to discuss policy, opportunities and events happening throughout the state as it relates to dementia care and services. The group is comprised of professionals and caregivers who have an interest in dementia.
- Long Term Services and Supports partnered with South Dakota State University Extension Office on Annie’s Project and served as panelists for caregiver education.
- The Alzheimer’s Disease Prevention Initiative is a grant funded through the Administration for Community Living. DHS has applied for this for two years; however, it has not been awarded.
- Ongoing analysis of the rate tiers for Medicaid supported Assisted Living settings to ensure individuals needing additional staff time are in the appropriate tier, including those influenced by dementia diagnoses.
- The South Dakota Long-term care Ombudsman (SDLTCO) program was awarded a two-year grant totaling \$201,184 for dementia care education. The funding comes from the Civil Monetary Penalty Fund, administered by the DOH. Thus far, through this funding, the Ombudsman program coordinated and sponsored training for 87 nursing facility staff members (completing 2-4 courses), in addition to over 200 long term care staff attended training on dementia care at the South Dakota Health Care Association (SDHCA) or South Dakota Association for Healthcare Organizations (SDAHO) conferences.

- Five Long Term Care Ombudsman are certified dementia practitioners through the National Council of Certified Dementia Practitioners as well as being certified as independent consultants and/or trainers through Positive Approach to Care (Teepa Snow). Long Term Care Ombudsman serve as advocates for residents in a nursing facility, assisted living setting or a community living home.
- The SDLTCO utilized Coronavirus Aid, Relief, and Economic Security (CARES) Act funds directed to the program through the Administration for Community Living to purchase Resident Experience Simulation Kits to utilize when presenting information on Resident Rights to Nursing Facilities and Assisted Living Centers.

For additional information or questions, please contact:

Heather Krzmarzick, Director
Long Term Services and Supports
Department of Human Services
Hillsview Plaza
3800 E Highway 34, c/o 500 E Capitol, Pierre, SD 57501
Heather.Krzmarzick@state.sd.us
(605) 773-2610

Tom Martinec, Deputy Secretary
Department of Human Services
Hillsview Plaza
3800 E Highway 34 c/o 500 E Capitol, Pierre, SD 57501
Tom.Martinec@state.sd.us
(605) 773-5990

Laura Streich, Deputy Administrator, Chronic Disease Director
Department of Health
Office of Disease Prevention and Health Promotion
615 E 4th Street, Pierre, SD 57501
Laura.Streich@state.sd.us
(605) 773-7046