

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

Prepared for the House
Health and Human Services Committee



By the South Dakota Department of Human Services

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Data

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

- Alzheimer's disease was the 5th leading cause of death in 2021. Dementia was the 9th leading cause of death in 2021 for Caucasians.
- Alzheimer's disease was the 4th leading cause of death from 2017-2021 for those 80+ years of age.
- 2021 was the lowest death rate in the last 10 years for Alzheimer's disease – 396 deaths. Dementia had 196 deaths in 2021.
- SD Nursing Facilities self-reported data via an assessment tool called the Minimum Data Set (MDS). For 3rd quarter 2022, Neurological – Alzheimer's Disease was noted at 16.64% and Neurological – Dementia was noted at 43.31% out of 4,729 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 funded 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 Family Caregiver Program, also administered through LTSS, provides support, both financially and with information and resources. This program serves 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 at approximately 25 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 ending 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 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. *On-going.*
- Seek and apply for other grant opportunities related to Alzheimer's and brain health. *Annually.*
- 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. *On-going.*
- 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. *On-going.*
- Prepare an annual report to the House Health and Human Services committee each year on the progress of the outlined efforts. *Annually in January.*

2022 Activities

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

The State Dementia Services Coordinator within LTSS allows for optimal collaboration amongst various programs and services. Specific activities of the Coordinator 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 the SD Chapter of the Alzheimer's Association.
- Meet regularly with staff from Active Generations 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.

In 2022, the Dementia Services Coordinator and DHS continued to build on many of the steps previously taken, in addition to some new opportunities, highlighted 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 website is currently a "microsite" managed by an entity separate from DHS' main website. The decision was made to absorb the microsite into the main DHS website. It is anticipated that the standard design and ability to maintain the new website, projected to launch Spring 2023, will lend credibility and easier access.

- 103 agency providers have enrolled in the Respite Care Registry.
 - 21 individual providers have enrolled in the Respite Care Registry.
 - 37 Individuals have received training through the Respite Care Certificate Program; the program was developed to provide individuals with the opportunity to become a Certified Respite Provider.
- 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.
- Researching opportunities with Trualta for on-demand caregiver education and wellness options:
 - 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 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 (SDSU) Extension Office on Annie's Project and served as panelists for caregiver education.
- The State Dementia Services Coordinator continues to coordinate 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 for two years; however, has not been awarded.

- Continued financial support of care for individuals supported by Medicaid with challenging behaviors, including those influenced by dementia diagnoses through the Add-On Payment process for nursing facilities.
- 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 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 Act (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. These simulation kits provide the opportunity for facility staff to experience life through the viewpoint of residents by utilizing tools which simulate the various disabilities experienced by residents including, low vision, impaired hearing, decreased mobility, dementia, and auditory hallucinations, etc.

Next Steps

In Long Term Services and Supports, our team focuses on providing opportunities to enable older South Dakotans and adults living with a disability to live independent, meaningful, and dignified lives while maintaining close family and community ties by promoting long term services and support to prevent or delay premature or inappropriate institutionalization. We consider a variety of factors in our strategic planning to serve older adults and those with disabilities, including Alzheimer's and dementia. As such, we anticipate the following activities or focuses in the future related specifically to Alzheimer's and dementia:

- LTSS all staff training to educate the team on the disease, communicating with persons with dementia and caregivers and strategies to assist in our work to serve persons with dementia and caregivers.
- Ongoing use of the Dementia Simulation Kits 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.
- Development of a Volunteer Ombudsman Program 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.
- 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.
- Rate methodology reviews scheduled for 2023 are Adult Day Service and Structured Family Caregiving, both of which are utilized by individuals living with dementia or Alzheimer's disease.
- Anticipate applying for the Alzheimer's Disease Prevention Initiative grant that is expected to be announced Spring 2023. It is a grant funded through the Administration for Community Living.
- Continue to enhance our reach and increase providers for the Lifespan Respite program.
- Implementation of Trualta for on-demand caregiver education and wellness option.
- Exploring additional avenues to meet caregiver needs.
- Ongoing facilitation of the Statewide Dementia Coalition by the State Dementia Services Coordinator to help advance statewide efforts around dementia.

For additional information or questions, please contact:

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