



Minnesota - North Dakota Chapter

Testimony
Senate Bill 2140
Human Services
Rep Matthew Ruby, Chair
March 17, 2025

Good morning Chair Ruby and members of the committee. My name is Melanie Gaebe and I am the North Dakota Public Policy Director for the Minnesota-North Dakota Chapter of the Alzheimer's Association. I am here to provide testimony in support of SB 2140 and to explain a bit more about how the Dementia Care Services Program works.

Alzheimer's and dementia touch our lives as caregivers, loved ones, friends, and family. When our loved ones start experiencing symptoms of cognitive decline, our lives are turned upside down as well. It is normal to start grieving the person we have known and wondering what comes next. There is no longer an "easy decision" about day-to-day life. There are so many things we take for granted every day; brushing our teeth, getting dressed, even paying bills. We perform these tasks without even thinking about it. Once cognitive decline begins, our loved ones need support to perform all of these activities. For a caregiver, it is overwhelming to navigate ever changing needs and symptoms alone, all while wondering if there is anyone who can help.

This is why the original language authorizing the Dementia Care Services program was passed in the 2009 session. The Dementia Care Services program is a contract for services located in the Adult and Aging Services section of Health and Human Services. The agency manages the contract and the Alzheimer's Association delivers the services. The contract and services are designed to provide support and education for caregivers after the person they are providing care for is showing symptoms of cognitive impairment.

Prior to the implementation of the program, caregivers found it difficult to move through next steps after symptoms develop. Caregivers didn't always know what resources and help were available much less how to get connected with those resources. Through the 15 year partnership between the State and the Alzheimer's Association, we have provided a lifeline for thousands of North Dakota families facing the unknown of caring for someone living with memory loss. Our Dementia Care Service Program staff provide a number of services, free of charge, to North Dakotans.

Our care consultation services offer individualized assistance, problem-solving, and resource identification for individuals with memory loss, as well as their family and professional caregivers. Through these consultations, individuals with dementia and their caregivers receive valuable one-on-one support, enabling them to better manage care and make informed decisions regarding services, resources, and treatments, including clinical trials.

Care consultations are provided at the most convenient location for those accessing the service. Our Dementia Care Service Program staff are based in Bismarck, Fargo, Grand Forks, Maddock, and Minot, and they travel throughout the state. Consultations can be conducted in person at our offices, in clients' homes, by phone, or virtually, ensuring that family members have flexible options to participate.

While care consultations are a keystone of the support we provide, the relationships and partnerships our staff cultivate are essential to successful consultations. We don't have all the answers and aren't professionals in every area a caregiver needs support, but we are able to provide referrals and make connections to the correct professionals.

The education opportunities the program offers are also extremely valuable. We provide comprehensive information and education to the general public about the symptoms of Alzheimer's disease and related dementias, the

benefits of early detection and diagnosis, available treatments, research opportunities, and services.

Our team provides dementia education tailored to specific audiences, including professionals in long term care, healthcare, and law enforcement and first responders. We also provide on-demand training for direct care providers who manage and care for individuals with symptoms of mild cognitive impairment or dementia. This on-demand training ensures the quality service providers who provide home and community based services have dementia specific training to best care for their clients.

Our innovative services enable individuals to remain safely in their homes and communities, thereby delaying the placement of individuals living with dementia in long term care facilities.

Dementia that is unmanaged negatively impacts the individual living with the disease, their caregivers, and ultimately creates a costly toll for communities and on the economy. The Dementia Care Services Program can help reduce higher costs related to dementia care. For example, studies have consistently shown that active management of dementia can improve the quality of life of affected individuals and their caregivers. Consider, for the current contract period, July 1, 2023 through December 31, 2024, this program has:

- Delivered **2,020** Care Consultations and Information and Referrals - for **1,217** caregivers on behalf of **698** people living with dementia, including **17** veterans living with dementia;
- Educated **2,932** community members across the state;
- Trained **110** law enforcement and **818** health care professionals; and
- Referred **57** people directly to the Aging and Disability Resource LINK.

Clearly, North Dakota Century Code 50-06-33 created a robust program to provide support for caregivers and people living with Alzheimer's or a related dementia. However, the code has not been updated in the years since it was originally written. What has changed in those years, is our understanding of Alzheimer's and dementia. Consider in the three years since I began my

career with the Association, three treatments that alter the underlying biology of Alzheimer's disease have been approved by the FDA. For the first time, we are able to give people living with Alzheimer's disease more time with their loved ones. Research is also expanding our ability to detect and diagnose dementia. We have more ability to test for biomarkers than ever before with more advancements in the research pipeline. All of this led us to believe it is time to update the language in 50-06-33 to reflect what we now understand about the continuum of the disease.

Years ago, we didn't really talk about Alzheimer's disease until it had progressed into the mid- to late stages, as though a person just woke up one day with late stage dementia. Now, we recognize the stages of disease progression and have even learned that biological changes are occurring in our brains up to twenty years before showing symptoms of cognitive decline. This is why we are proposing the change from a definition of "dementia" as criteria for accessing services to focus on who our clients are. Many of our clients come to us through referrals from our partners and haven't received a formal diagnosis of dementia prior to seeing us.

The changes proposed to NDCC 50-06-33 are technical updates and don't alter the purpose or goals of the existing Dementia Care Services Program. The changes are simply to bring the authorizing language into alignment with what has changed through research and ensure we continue providing services to the North Dakotans who need to know they aren't navigating Alzheimer's disease and related dementias alone.

Thank you for your time, I'm happy to take questions.