# Testimony

# House Bill 1012 – Nikki Wegner, Alzheimer's Association, ND/MN Chapter Senate Appropriations Committee Senator Ray Holmberg, Chairman March 11, 2021

Chairman Holmberg and members of the committee, my name is Nikki Wegner and I am the Western North Dakota Program Manager for the Alzheimer's Association. I am one of six staff who provide programs and supports to North Dakota residents impacted by Alzheimer's and other dementia.

Thank you for the opportunity to speak with you today on House Bill 1012.

We appreciate the continued funding included in this bill for the Dementia Care Services Program (DCSP), however we are opposed to the cut of \$168,000 that was passed by the House. In fact, we are asking the committee to consider an increase of \$132,000. I will explain why we believe this funding increase is necessary to meet the growing needs of North Dakota residents.

This longstanding partnership between the State and the Alzheimer's Association has provided a life-line for thousands of North Dakota families when they need it most, when they are faced with a dementia diagnosis and growing care needs for their family member. This program has also provided dementia education for tens of thousands of community members and professionals across the state.

I encourage you to read the written testimony from Denise Fettig-Loftesnes. Her family was shocked by back-to-back dementia diagnoses of her father and mother. Denise and her siblings have received critical assistance through our program. And you will hear from Amber Moen today as well, who also received support that allowed her and a network of caregivers to provide care for her mother at home for years before making the hard decision to place her mother in a long term care facility.

With the recent Olmstead Settlement Agreement, we understand that the legislature and the administration are looking carefully at how North Dakota can transform its long-term care system, so that people can remain at home with access to the care that they need. The DCSP supports and encourages access to available home and community-based services.

The UND Center for Rural Health studied the first few years of the DCSP at the request of the legislature. **Over a 42-month period, with an investment of \$2 million, the state saved an** 

estimated \$39 million in long-term care costs from reduced hospital and emergency related services and delays in placing a person with dementia in long-term care facilities. You can see more details on that study in the document submitted with my written testimony. This document also includes a full overview of the DCSP, has a more in-depth explanation of our services, the total numbers of people-served, as well as a map of North Dakota showing our service numbers by county.

The goals of the DCSP are 1) to improve care, quality of life, and health outcomes, and 2) to reduce total cost of care associated with the disease for individuals, families and ultimately the state budget.

In the current contract for the DCSP<sup>2</sup>, the Alzheimer's Association has:

- Delivered 1,744 Care Consultations for 1,229 caregivers on behalf of 640 people living with dementia.
- Educated 2,054 community members across the state.
- Trained 135 law enforcement and 1,198 health care professionals.
- Referred 120 people to Family Care Services Program.

While professional training across the state is a valuable asset, it does not represent the largest impact of this program.

The greatest value of the DCSP remains supporting people directly impacted by dementia. We educate, support and provide resources to individuals living with dementia, their caregivers and families. The innovative services provided promote early detection and diagnosis, care coordination, effective caregiver training, support groups, and planning for the future.

Dementia that is unmanaged negatively impacts the individual diagnosed, their caregivers and ultimately creates a costly toll for communities and on the economy. Consider a few facts from our research:

# **State Costs**

North Dakota's 2020 Medicaid costs for people living with dementia were \$190 million – and that cost is expected to rise 13.2% by 2025.<sup>3</sup>

<sup>&</sup>lt;sup>1</sup> Center for Rural Health Assessment of North Dakota Dementia Care Services Program July 2013, p. 6

<sup>&</sup>lt;sup>2</sup> Data collected by the Alzheimer's Association for the Dementia Care Services Program contract July 1, 2019 through November 30, 2020

<sup>&</sup>lt;sup>3</sup> 2020 North Dakota Alzheimer's Statistics

The average annual per person Medicaid cost for someone without dementia is \$374, versus \$8,779 for someone with dementia – that means that a person with dementia costs Medicaid **23 times more** than a person without dementia.<sup>4</sup>

#### **Family Costs**

Out of pocket costs for an individual with dementia are 3.5 times greater than for those without. <sup>5</sup>

We estimate that the value of care provided by North Dakota's 30,000 unpaid dementia caregivers is \$454 million.<sup>6</sup>

Why are these costs so high?

- 1. Dementia complicates the management of other conditions,
- 2. People with dementia have more hospitalizations, in fact, twice as many as other older adults.<sup>7</sup>
- 3. And people with dementia have more emergency room visits.

The DCSP can help reduce these high costs. For example, studies have consistently shown that active management of dementia can improve the quality of life of affected individuals and their caregivers. And that is where the Dementia Care Services Program enters the equation for North Dakota.

# **Growing Need**

The need for care and support across North Dakota is growing. One in 10 people age 65 and older are living with Alzheimer's. In 2017, we estimated there were 14,000 North Dakotans living with Alzheimer's. Today, we estimate that number to be 15,000. We expect those numbers to rise to 16,000 by 2025, an increase of 14% in just 8 years. 10

Additionally, the Department of Human Services has indicated a need for a self-paced, online professional dementia education program to train Qualified Service Providers (QSPs). We support this because we know that staff training is an important determinant of quality

<sup>&</sup>lt;sup>4</sup> Alzheimer's Association 2020 Alzheimer's Disease Facts and Figures, p. 46

<sup>&</sup>lt;sup>5</sup> *Ibid, p. 47* 

<sup>&</sup>lt;sup>6</sup> 2020 North Dakota Alzheimer's Statistics

<sup>&</sup>lt;sup>7</sup> Alzheimer's Association 2020 Alzheimer's Disease Facts and Figures, p. 48

<sup>&</sup>lt;sup>8</sup> Alzheimer's Association 2020 Alzheimer's Disease Facts and Figures, p. 12

<sup>&</sup>lt;sup>9</sup> *ibid*, p. 18

<sup>&</sup>lt;sup>10</sup> 2020 North Dakota Alzheimer's Statistics

dementia care across the long-term care spectrum.<sup>11</sup> The Alzheimer's Association has developed a program to deliver evidence-based online dementia training based on our nationally recognized Dementia Care Practice Recommendations.

### **Request for Funding Increase**

To respond to this growing need, we are seeking an 11% increase in funding from \$1,200,000 to \$1,332,000. Please note that this program has never received a funding increase since it began in 2010.

Without these dollars, we will be unable to meet the increased demand for care consultation, professional training and community education, leaving residents with less access to these vital services that help to keep those living with dementia at home in the community.

We look forward to the continued partnership with the State to better support North Dakota residents and reduce long-term costs to the State. With the State's continued support, the Alzheimer's Association aims to ensure that everyone in North Dakota has access to the services proven to improve disease management and increase family support. We ask this committee to support the funding necessary to continue these vital services and expand our ability to serve the growing need.

Thank you for your consideration. I would be happy to answer any questions you may have.

<sup>&</sup>lt;sup>11</sup> The Gerontologist, Volume 58, Issue suppl\_1, February 2018, p. S103–S113