MINNESOTA
BOARD ON AGING

Progress Report

Funding for Support for Caregivers of People with Amyotrophic Lateral Sclerosis (ALS)

December 4, 2024

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Minnesota Statutes, Chapter 3.197, requires the disclosure of the cost to prepare this report. The estimated cost of preparing this report is $6,698.

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Contents

I. Legislation

Minnesota Statutes 2023, section 256.9755

Subdivision 1. **Program goals.**

It is a goal of all area agencies on aging and caregiver support programs to support family caregivers of persons with amyotrophic lateral sclerosis (ALS) who are living in the community by:

(1) promoting caregiver support programs that serve Minnesotans in their homes and communities;

(2) providing, within the limits of available funds, the caregiver support services that enable the family caregiver to access caregiver support programs in the most cost-effective and efficient manner; and

(3) providing information, education, and training to respite caregivers and volunteers about caring for, managing, and coping with care for a person with ALS.

Subd. 2. **Authority.**

The Minnesota Board on Aging shall allocate to area agencies on aging the state funds which are received under this section for the caregiver support program in a manner consistent with federal requirements. The board shall give priority to those areas where there is a high need of respite services as evidenced by the data provided by the board.

Subd. 3. **Caregiver support services.**

Funds allocated under this section to an area agency on aging for caregiver support services must be used in a manner consistent with the National Family Caregiver Support Program to reach family caregivers of persons with ALS, except that such funds may be used to provide services benefiting people under the age of 60 and their caregivers. The funds must be used to provide social, community-based services and activities that provide social interaction for participants. The funds may also be used to provide respite care.

Subd. 4. **Report.**

By January 15, 2025, and every other January 15 thereafter, the Minnesota Board on Aging shall submit a progress report about the caregiver support grants in this section to the chairs and ranking minority members of the legislative committees and divisions with jurisdiction over human services. The progress report must include metrics of the use of the grant program.

II. Introduction

In 2022, the Minnesota Legislature appropriated $25 million in funding to support Minnesotans living with Amyotrophic Lateral Sclerosis (ALS) and the family, friends and neighbors caregiving for them. This bipartisan legislation, introduced by the late Senator David J. Tomassoni elevated issues many Minnesotans were unaware of including:

- ALS is a nervous system disease that affects nerve cells in the brain and spinal cord. It is a progressive disease which causes loss of muscle control.
- The exact cause of the disease is not known. About 400 people in Minnesota have ALS, an on average received their diagnosis at 56 years old. Nationally there are 30,000 individuals with ALS. The average life expectancy after diagnosis is 2-5 years.
- ALS often begins with muscle twitching and weakness in an arm or leg, trouble swallowing or slurred speech. Eventually ALS affects control of the muscles needed to move, speak, eat, and breathe. There is no cure for this fatal disease.

Citation: Mayo Clinic

Many families impacted by ALS do not have the financial resources to bring in the care they need to support the individual, at home during this aggressive disease timeline. While there is a network of certified ALS clinics and disease-specific organizations available to offer resources and guidance, the experience is challenging, and often devastating.

The 2022 legislation has strengthened the network of support for individuals with ALS and their family and friend support systems.

The statute specified that $5 million of that funding should be used to for caregiver support programs, including ALS specific respite services and specified that the services should follow the rules and guidelines of the National Family Caregiver Support Program (NFCSP). The NFCSP is funded through the federal Older Americans Act (Title III-E) and is distributed through the Minnesota Board on Aging, to area agencies on aging who contract with providers across the state to provide services. This one-time appropriation will end in June 2026 unless extended by the legislature.

The Minnesota Board on Aging (MBA) designated the Arrowhead Regional Development Commission's (ADRC) Arrowhead Area Agency on Aging (AAAA) to administer ALS funding. AAAA issued a Request For Proposal and ultimately contracted with the Minnesota Chapter of the ALS Association (ALSA) to 1) promote caregiver support programs that serve Minnesotans in their homes and communities, 2) provide within limits of available funds, the caregiver support services that enable the family caregiver to access caregiver support programs in the most efficient manner, and 3) provide information, awareness, education and training to inform caregivers and volunteers about caring for, managing and coping with care for a person with ALS. The funds were also available to coordinate respite for Minnesotans caring for someone with ALS.

A portion of the funding was allocated to Minnesota's seven area agencies on aging (AAA) to cover the costs of training service providers across the state, currently contracted with the AAAs. These providers include upwards of 90 trained Caregiver Consultants who help caregivers with problem-solving, provide resource information, navigation support and consultation on planning care for older Minnesotans. Since individuals diagnosed with ALS can be in their 50s, the MBA sought permission from the Administration on Community Living (ACL) to expand the Older Americans Act Title III-E, NFCSP eligibility criteria for caregiving support programs. The NFCSP authorizes use of Title III-E funding for caregiving services provided to:

An adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual of any age with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction (OAA Sec. 302, paragraph 3).

MBA received permission from ACL's Regional Administrator to deem ALS to be a "neurological and organic brain dysfunction", allowing individuals caring for a person with an ALS diagnosis to be eligible to receive Title-E NFCSP services. The expanded criteria will offer a path for sustainability of caregiver support for those caring for someone with ALS beyond the life of this funding. Our priority has been to use a portion of the funding to build the capacity of our existing and future Caregiver Consultant providers to be equipped to understand the needs of a person with ALS and their family caregiver. The training is provided by ALSA. The training includes self-directed online modules and a virtual or in-person training.

ALSA named the respite program supported by this funding, the Senator Tomassoni Caregiver Support Program, in honor of the late State senator. ALSA staff work to identify caregivers in need of respite support to access respite funds to receive respite by either 1) hiring someone privately and utilizing a Fiscal Management Service (FMS) to coordinate payment and employment-related tasks or 2) by contracting directly with a homecare agency to provide care.

Purpose of report

This report is meant to give an accounting of the funds spent and the people served at this point in the funding. After the legislation passed in Spring 2022, there was a period of planning and selection of an organization to deliver the Caregiver Support Services defined in Statute. There were no administrative funds included in the legislation, so the MBA and AAAA assigned various staff to assist with rolling out the program. The Senator Tomassoni Caregiver Support program launched in November of 2023. Metrics of utilization and spending are included in the sections below.

III. Outcomes

The MBA and AAAA receive monthly reports from ALSA. Initially, ALSA did not collect some demographic information, so the first two months of reporting included limited demographics, and then expanded demographic reporting throughout reporting in 2024. Overall, the numbers of people served, hours of respite used and paid for is in line with what was discussed during the planning phase. They align with ALSA's predictions based on their client base and referring clinics. Most of the recipients of the funding are white, over age 45 and are spread out around the state. To date there have been no respite support funding to a caregiver identifying as American Indian and Alaska Native (AI/AN). There has been participation of Caregiver Consultants, contracted under the Minnesota Indian Area Agency on Aging (MIAAA) who have completed the online modules and attended the virtual live training. Having Caregiver Consultants from tribal communities receive the ALS training is key to future outreach in tribal communities, to identify families impacted by ALS. Research has noted a lower incidence of reporting this rare disease among AI/AN communities than in the rest of the population (citation).

A. People served in the Senator Tomassoni Caregiver Support Program

Demographic information covers the period from January – October 2024. Additional information about the total amount of people served, respite provided, and cost is available from the beginning of the program in November of 2023 through October of 2024.

People Served and Respite Provided

	Hours of Respite	Caregivers Receiving Grants
November – December 2023	582	18
January – October 2024	24,031	120
Life of the Program to Date (November 2023 – October 2024)	24,613	138

Below are tables reflecting the race and ethnicity, age, and region of residence information for participants in the Tomassoni program from January – October 2024.

Race and Ethnicity, January – October 2024

Race/Ethnicity	Caregivers	Care Recipients
White non-Hispanic	86%	90%
White Hispanic	2%	1%
American Indian/Alaskan Native	0%	0%

Race/Ethnicity	Caregivers	Care Recipients
Asian	2%	1%
Black/African American	4%	4%
Native Hawaiian or Other Pacific Islander	0%	0%
Other Race	5%	4%
2 or More Races	0%	0%

Age, January – October 2024

Age	Caregivers	Care Recipients
18 – 34	6%	5%
35 - 44	5%	3%
45 – 54	17%	15%
55 - 64	21%	22%
65 - 74	40%	39%
75 - 84	11%	15%
85+	1%	2%

Region of residency, January – October 2024

Not surprisingly, most of the people who utilized respite services were from the more highly populated metropolitan areas. However, each area of the state did include caregivers who needed respite. As noted earlier, no respite services have been provided to a member of a tribal community. We anticipate that to change as additional Caregiver Consultants are trained, and outreach in tribal communities is conducted. In 2023 and 2024, MIAAA included four tribes. In 2025, MIAAA will include 11 tribal nations in Minnesota. Training for staff, providers, and caregivers in tribal communities across the state will likely expand in 2025.

Area Agency on Aging Region	Caregivers	Care Recipients
Arrowhead Area Agency on Aging	6%	6%
Central Minnesota Council on Aging	14%	14%
Dancing Sky Area Agency on Aging	3%	3%
Minnesota River Area Agency on Aging	6%	6%
Trellis	61%	61%
Southeastern Minnesota Area Agency on Aging	9%	9%
Minnesota Indian Area Agency on Aging	0%	0%

B. Cost of Respite Provided

Financial information is available for the life of the grant through October 2024. The ALS Association was awarded $4,650,000. From that amount, they have hired a full-time staff person for 3 years and contracted for some training needs. The rest of the funding goes for respite grants to caregivers.

Funds for respite grants, November 2023 – October 2024

Original Available for Respite Grants	$4,061,750
Awarded through Respite Grants	$2,895,000
Awarded Funds Spent	$1,040,744
Awarded Funds Unspent	$517,122
Remaining Funds to be Awarded	$1,683,872

A note regarding the unspent awarded funds in the table above. There have been circumstances where people who were awarded the grant did not spend their entire grant amount. Funds being unspent often happens because the person with ALS passes away before the entire grant is spent. However, in some cases, a person may not fully use their entire grant over the course of 12 months and the grant funds do not carry over year to year.

A more detailed break-down of costs is available for the period of January – October of 2024. Every recipient of a respite grant has indicated that they would not have been able to afford respite without this funding. Recipients used a combination of agency help and, utilizing a Fiscal Management Service, privately hired workers to provide the needed respite.

Types and costs of respite provided, January – September 2024

	Hours	Cost
Respite through a **homecare agency**	8,349	$376,142
Respite through **FMS-paid provider**	15,683	$534,407
FMS Fees		$38,610
Total	24,032	$949,159

C. Training for the Aging Network

At the time of this report, eight trainings have been offered by the ALS Association for people caregiving and professionals supporting caregivers. 27 family or friend caregivers participated as well as two paid caregivers and 65 caregiver consultants.

Training	Audience	Date
Tomassoni Training and Learning Lab (combined)	Caregivers and Professionals	3/26/24
RestUp Workshops	Caregivers	5/3/24 and 5/4/24 10/4/24 and 10/5/24
Tomassoni Virtual Training	Caregivers and Professionals	6/13/24 and 11/13/24
Tomassoni Learning Lab	Caregivers	6/25/24

D. Future Projections

In the remaining months of the fourth quarter (November – December 2024), the ALS Association projects they will serve 12-14 new caregivers, obligating $20,000 to each for a 12-year period to pay for respite. Through the remainder of the funding period (January 2025 – June 30, 2026) AAAA and ALSA staff anticipate obligating the entire amount available for respite grants. The monthly draw down of funds has steadily increased over the past year and is projected to be exhausted prior to the end of the funding period.

Staff representing the Minnesota Board on Aging, Arrowhead Area Agency on Aging and ALS Association will continue to meet monthly to review progress and strategize ways to reach more people caregiving for a person with ALS. MBA staff will work closely with the expanded MIAAA to engage providers to expand the availability of Caregiver Consultation in their respective communities, and support Caregiver Consultants to attend the ALS training.

Additional opportunities for ALS training will be available in 2025, funded through AAA contracts with providers. MBA is planning for supplemental training for Caregiver Consultants who have already attended trainings this past year. Work is underway to establish a referral process for ALSA and ALS specific clinics to refer family and friend caregivers to Caregiver Consultants in their communities for additional support. This referral process will be built into the existing path that individuals with ALS and their family and friend caregivers intersect and could expand to new pathways. We are optimistic that there will be increased awareness of support for individuals and families impacted by ALS.

E. Impact on Minnesotans Caregiving

Impact has been shared through comments made directly to ALSA staff from the caregivers that have been served by this program. Below are a few of the many grateful comments that illustrate the impact of the program:

“Living with ALS is incredibly scary for the entire family. the Tomassoni grant has made it possible to have the help we needed without worrying about money.”

“The caregiver support allows me to not worry about my wife during the day and allows me to work, take care of our 10-year-old daughter and do household chores without feeling like I'm neglecting my wife. The funding has also been a significant stress reducer and I feel, allows me to be a better husband and father knowing I have assistance.”

“Having paid caregivers in our home reduces the tasks that I otherwise would have to do, such as meal preparation, bathing, dressing, taking my wife to the toilet, getting her ready for bed at night, etc. While I still do all of those things, the help I'm getting certainly eases my burdens.”

“I have been able to get my own health appointments done, run errands, shopping and take care of my mental health by giving me a break. I am grateful for this, thank you!”