

Age-Friendly Status Check

CAREGIVING AND DEMENTIA

SEPTEMBER 2021



AGE-FRIENDLY MINNESOTA

Caregiving and Dementia

We will be prepared to care for each other as we age, and be supported in our roles as caregivers.

Background

This document is one of eight briefs that explore current approaches and impact of the Minnesota Board on Aging, Minnesota's aging network¹ and Department of Human Services. A better understanding of the foundation provided by our existing work will guide us as we develop strategies for Age-Friendly Minnesota. We aim to stretch our thinking about what aging can and should mean for all Minnesotans—creating policies, communities, and services that see age in everything and empower us with what we need to live with dignity and autonomy at every stage.

The briefs are not exhaustive but aim to capture major ideas, prompt needed questions and discussions, and help us identify priority opportunities for greater impact and better outcomes. All briefs are available at the Age-Friendly Minnesota website.

Overview

Minnesota has approximately 640,000 family, friends, and neighbors helping to care for an older adult, providing care estimated to be worth \$8.6 billion a year,² exceeding Minnesota's Medicaid expenditures for nursing homes and long-term services and supports. This informal (or unpaid) caregiving is an integral piece of Minnesota's healthcare system.

Caregiving for someone with dementia is typically more expensive and emotionally, physically and mentally taxing than other caregiving situations. Although dementia is not a normal part of aging, it is primarily a disease of age. As more people live longer lives, the number of Minnesotans with dementia continues to rise. Approximately 100,000 Minnesotans currently have Alzheimer's disease or other dementias, all of which impair brain function; these Minnesotans are cared for by around 170,000 unpaid caregivers, who do work valued at \$3.3 billion per year.³

Another facet of this work are the varying cultural norms and perceptions related to aging, caring for aging family members, and dementia itself. As Minnesota's population continues to become more racially and culturally diverse, it will become increasingly important to develop inclusive, equitable services that reflect knowledge of and respect for these cultural differences.

The State of Minnesota has become a national leader in supporting people with dementia and their caregivers. In 2009, the Legislature tasked the Minnesota Board on Aging (MBA) with establishing the

¹ The Older Americans Act of 1965 established a national network of federal, state, and local agencies to plan and provide services that help older adults, including American Indian and Alaska Native elders, to live independently in their homes and communities. This interconnected structure of agencies is known as the aging network.

² AARP Public Policy Institute, [Valuing the Invaluable](#) (2019)

³ Alzheimer's Association of North Dakota and Minnesota

Alzheimer's Disease Working Group (ADWG) and making recommendations for policies and programs to prepare Minnesota for future increases in dementia. This cross-sector working group produced a 2011 report titled, [Preparing Minnesota for Alzheimer's: The Budgetary, Social, and Personal Impacts](#), as well as a review and update to this report—[Alzheimer's Disease Working Group, Legislative Report](#)—in 2019. Within the State of Minnesota, work related to dementia and caregiving is led primarily by the MBA, Department of Human Services (DHS), and Department of Health. Other statewide leaders include the Alzheimer's Association of North Dakota and Minnesota, and the University of Minnesota's Center for Aging.

The aging network has invested in dementia work in a number of key ways:

- Area Agencies on Aging (AAAs), Eldercare Development Partnership, Dementia Grants, and Live Well at Home® all play key roles in strengthening supports for people with dementia and their caregivers.
 - AAAs undertake work such as:
 - Developing caregiver resources, such as caregiver consultation and respite services
 - Expanding available culturally and linguistically appropriate caregiver support for various ethnic and cultural communities
 - Connecting with employers to help them better understand and support working caregivers
 - Partnering with other organizations and sectors to identify collaborative solutions.
 - Senior LinkAge Line (SLL) is a free statewide service of the MBA in partnership with Minnesota's AAAs. The SLL assists older Minnesotans and caregivers by connecting them to local resources. All SLL staff have completed training in caregiving and dementia.
 - Live Well at Home® grants fund projects focused on expanding the capacity of Long-Term Services and Supports (LTSS) to help older Minnesotans remain in their homes and communities of choice. These grants include funding for capital and renovation grants; LTSS development, including community and caregiving support; and core Home and Community-Based Services focused on strengthening and developing alternatives to nursing homes and other residential services.
 - The MBA Dementia grants program was created in 2015 to support regional and local projects focused on: 1) increasing awareness of dementia; 2) promoting cognitive testing and early diagnosis; and 3) supporting caregiving by family, friends and neighbors. The Legislature has appropriated \$1.5 million for this program in each biennium since the 2016/2017 biennium.
 - Minnesota's successful ACT on Alzheimer's initiative, which began to be implemented in 2015, was a public-private effort focused on community-level support for people with dementia. ACT on Alzheimer's was used as a model for Dementia Friendly America, a national network of communities, organizations, and individuals seeking to ensure that communities across the U.S. are equipped to support people living with dementia and their caregivers.

Minnesota's investments in caregiving and dementia are significant and commendable, but as the population ages, the scope and acuity of needs will increase and require additional investments from different angles. The return on investment is multi-faceted—among other things, greater caregiver

support relieves pressure on adult protective services, delays or prevents moves into long-term care, and results in better physical and mental health of caregivers, allowing them to provide care longer.

Impact and Examples of Current Work

The following section describes themes that emerged related to the impacts of work focused on Caregiving and Dementia, followed by examples of strategies and grants⁴ that help demonstrate how it is being carried out. The work described below is primarily from 2019-2021.

We lead statewide efforts to educate, support, and advance issues related to caregivers.

The Minnesota Caregiving Coalition, coordinated by the MBA, is a statewide coalition of more than 15 unique organizations that meets monthly to share program updates and to discuss best practices for caregiving support services and training or funding opportunities. Caregiving Coalition meetings are an opportunity for providers across the state to discuss services and lessons learned. These discussions have been especially valuable while adjusting services to the COVID-19 pandemic.

As a member of the Center for Health Care Strategies (CHCS) Helping States Support Families Caring for An Aging America, Phase II Initiative, the MBA is enhancing and developing strategies to assist family, friends, and neighbors who are caregiving. This cross-sector partnership includes team members from DHS, the Alzheimer's Association, and Health Partners.

We support and expand the use of effective models for providing caregiver support.

Caregiving is integral to supporting each other as we age. While dementia is primarily a disease of age, other conditions—such as Parkinson's disease, Traumatic Brain Injuries, strokes, and Down syndrome—can cause or increase the risk of dementia.

New models and programs are being developed that both support and empower caregivers, who have a difficult job and often need help to prevent burnout and safeguard their own wellbeing. When compared to caregivers of individuals without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties.⁵

Area Agencies on Aging, Live Well at Home® grants and MBA Dementia grants help extend the reach and impact of caregiver support programs in a number of ways. Namely, they help identify and train individuals to deliver these programs; fund provision of the programs to caregivers who need them; promote and educate partner organizations and service providers about the programs; provide continuing education for those delivering the programs; and form groups or networks where those individuals working with caregivers can learn from and support each other. Below is more information about key models and examples of how they are being employed.

- **Caregiver Consultants:** Trained professionals who help caregivers on an individual basis with problem-solving, information, skills, and emotional support. Nearly 80 Caregiver Consultants are available throughout the state, and interested caregivers can learn more through Senior LinkAge Line.

⁴ All Live Well at Home® grants referenced in this brief were awarded in State Fiscal years 2018-2021. Numbers shared to illustrate the impact of the most recent grants are likely to increase over the course of the grant cycle.

⁵ *Alzheimer's Disease Facts and Figures* report, Alzheimer's Association, 2020.

Caregiver Consultants complete over 30 hours of an MBA-designed, hybrid curriculum, including culturally responsive modules focused on dementia in a variety of communities, including African American, Hmong, Somali, American Indian, and Latino. Some Caregiver Consultants in Minnesota also have received training related to homelessness.

- **REST (Respite Education and Support Tools):** An evidence-based respite-training program that is used statewide. There are a variety of trained REST professionals, including more than 400 REST Companions, who provide respite; almost 50 REST Trainers, including two Spanish-speaking trainers (as a result of a Live Well at Home® grant with Centro Tyrone Guzman); four REST Master Trainers; and one of the only nationally trained REST Regional Trainers.
- **REACH Community (Resources for Enhancing Alzheimer’s Caregivers in the Community):** REACH Community is a dementia caregiving program that empowers caregivers to problem-solve challenges that arise from caregiving. There are more than 125 trained REACH providers in Minnesota.
- **PEARLS (Program to Encourage Active, Rewarding Lives):** A program that educates older adults about depression and helps them develop skills for self-sufficiency and more active lives.
- **Powerful Tools for Caregivers:** An evidence-based six-week education program focused on supporting caregivers while they provide care.
- **Trualta:** An online training platform designed for caregivers. Minnesota’s approach uses Caregiver Consultants to help families, friends, and neighbors who are caregiving find appropriate training on Trualta to support them in their caregiver roles, reduce stress, and prevent burnout. The platform consists of curated collections of modules, called badges. The MBA is working closely with Tribal Nations to create the first ever Indigenous Caregiving badge.

We expand availability of respite services.

Opportunities for respite care are of fundamental importance for most caregivers, providing much-needed time to attend to other things or simply do something they enjoy. Respite may be provided by a professional, a volunteer, a family member, friend or may also be provided in a care setting. Approaches to respite include those listed above, among others. Many AAAs helped providers establish virtual respite services during COVID-19 to allow caregiver support to continue during this uniquely difficult period.

Adult Day services are another type of respite care. These services provide activities to meet the health and social needs of a care recipient, while simultaneously providing a break for the caregiver. Activities may include participating in community groups, age-appropriate tasks, and community integration opportunities.

We provide culturally appropriate outreach, support, and information to older adults who are Black, Indigenous, and people of color.

Norms, beliefs, and expectations related to aging can vary considerably across cultures; this is very true as it relates to dementia. Providers must be knowledgeable, respectful, and inclusive. Friendly, caring, and well-intentioned staff are important but not enough; people's use and experience of services are just as informed by cultural traditions, religious practices, and dementia-awareness.⁶

The Alzheimer's Association reports that an overwhelming majority (from 84% to 92%) of Black, Hispanic, Asian, and Native American survey respondents said it was important for Alzheimer's and dementia care providers to understand their ethnic or racial background and experiences. However, most feel that people in their communities do not have access to such providers. In addition, half or more of non-White caregivers say they have experienced discrimination when navigating health care settings for their care recipient.⁷

All AAAs are working to expand and strengthen services to culturally diverse older adults—for example, by working with culturally-specific organizations that provide caregiver support to improve services to caregivers who are members of those communities.

A recent Live Well at Home® grant funded CAPI USA to expand culturally and linguistically appropriate support for low-income Hmong older adults and caregivers in northern Hennepin County. CAPI supported over 60 Hmong caregivers with transportation, grocery shopping, and assistance completing public benefit applications.

A recent MBA Dementia grant supported Volunteers of America Minnesota to increase dementia awareness by promoting and uplifting cultural differences and to respond to community needs in respectful and dignifying ways. This involved training 180 staff from the Minneapolis and Saint Paul Housing Authorities and Volunteers of America Minnesota, and reached nearly 2,000 community members, including African American, Hmong, and East African older adults.

We provide dementia awareness and caregiver support to older people who are LGBTQ.

Older adults who are LGBTQ face particular challenges related to aging. LGBTQ older adults are more likely to be financially insecure and to live alone, less likely to have children to help care for them, and often lack culturally competent healthcare, service providers, and senior housing.⁸ Many have faced years of discrimination that can continue into older age. The aging network is working to better understand and build capacity related to serving LGBTQ older adults.

Recent MBA Dementia grants have helped support LGBTQ older adults related to caregiving and dementia.

- Northwoods Caregivers in Bemidji is working to increase awareness and early identification of dementia and to connect caregivers to each other, including outreach to Native American and LGBTQ+ communities. It is building on current partnerships with Red Lake, White Earth, and Leech

⁶ ["Cultural sensitivity and awareness,"](#) Alzheimer's Society United Kingdom

⁷ [Special Report: Race, Ethnicity, and Alzheimer's in America,](#) Alzheimer's Association, 2021.

⁸ Williams Institute, UCLA School of Law

Lake Nations as well as Bemidji State University and Northwest Technical College, and a new LGBTQ+ Cultural Consultant.

- Rainbow Health's (formerly JustUs Health) project, Dementia Awareness for LGBTQ+ and HIV-Positive Minnesotans, has provided awareness training to almost 40 people of different genders, races, and geographies and is working to offer an LGBTQ+ Dementia Caregiver Support Group.

We support and partner with Dementia Friendly Community initiatives.

The State of Minnesota supports dementia friendly communities, which foster the ability of people living with dementia to remain in community and engage and thrive in day-to-day living. Dementia friendly communities respond in part to the fact that dementia is as much a social condition as a medical one. While the ACT on Alzheimer's initiative is no longer active, many communities continue to take up dementia friendly efforts—independent from or in tandem with age-friendly communities work.

AAAs, Live Well at Home® grants, and MBA Dementia grants all support efforts to advance dementia-friendly communities in various ways. For example, in 2020, one AAA successfully reignited collaboration in the region by hosting a virtual regional conversation related to dementia involving Dementia Friends Champions, Memory Café leaders, caregiver consultants, caregivers, and ACT on Alzheimer's leads.

We engage across sectors to build community support and understanding of people with dementia and caregivers.

As part of a community-level approach, we also cultivate active engagement of other sectors that can play important roles in people's daily lives—such as faith communities and local businesses. Some of this work is accomplished through the Dementia Friends program.⁹ Minnesota currently has more than 21,000 Dementia Friends.

- Through a Live Well at Home® grant, TRUST, in Minneapolis, is assessing congregations' ability to help older adults and caregivers, offer Dementia Friends training, and provide care coordination. The Gathering, a popular group respite program, was put on hold due to COVID-19. TRUST also offers a durable goods loan program that includes walkers, canes, wheelchairs, etc.,
- With support of a MBA Dementia grant, Barnesville Area HELPERS in Barnesville is expanding community awareness of dementia by providing individualized dementia friendly information sessions to local businesses, banks, students, clergy, and the police, fire, and ambulance crews. Barnesville Area HELPERS staff have also completed the Alzheimer's Group Facilitators training.

We partner with healthcare providers to establish protocols that better help older patients being discharged and their caregivers.

The hospital discharge process presents an opportunity to set the stage for a smooth transition to home and reduce readmissions. This involves the caregiver as well as the patient. Sometimes people become caregivers when a family member or friend is discharged from the hospital, and life will not be returning to normal. Hospital discharge is an opportunity to reach out to a caregiver with information and training about the role they are about to assume—for their own benefit as well as that of the person being discharged.

⁹ A Dementia Friend is someone who attends a one-hour session to increase their understanding of dementia and learn how to make a difference for people affected by dementia in their communities.

Some AAAs are working with healthcare providers to establish new procedures in this regard. Among other examples, one has worked with a regional healthcare provider to begin to implement referral protocols—including Senior LinkAge Line, local Caregiver Consultants, and the Alzheimer’s Association—upon discharge for people with dementia. Another has worked with a regional foundation on funding opportunities related to improving hospital discharges for tribal elders.

We provide caregiver support as part of an array of home- and community-based services.

Some providers and grantees offer a large menu of services—including caregiver support—focused on helping older people stay well and safe in their homes and communities. An older adult can choose which services they need and may bundle caregiving support with other assistance. This often is referred to as wrap-around services, which support the caregiver in other areas, such as transportation, chore services, or grocery delivery, in order to address the bigger picture of a caregiver’s needs. Examples of Live Well at Home® grants that illustrate this include:

- Volunteer Services of Carlton County serves Aitkin and Northern St. Louis counties with one-stop wrap-around services focused on assisted transportation, chore services, in-home and group respite, caregiver support and education, GrandCare and Carlton Wellness Center activities. The organization provided over 700 hours of chore services, almost 900 hours of caregiver respite, more than 15,000 one-way rides, and over 1,400 caregiver counseling sessions.
- ElderCircle in Grand Rapids is enhancing current programming to support aging in place and maximize independent living for older adults and caregivers in Itasca and St. Louis Counties. Throughout the FY 2021 grant period, ElderCircle has implemented an iPad Lending Library, delivered around 500 grocery orders, offered health and wellness sessions to almost 50 participants, and connect with 10 caregivers in support groups.

We use the arts and music to support people with dementia and caregivers.

Music and the arts can transcend some of the loss and challenges that accompany dementia and allow people to connect with each other in a powerful way. We support this approach in a variety of ways.

- One AAA serves on the advisory committee of a local theater, using arts as dementia support. This includes outreach to the Somali community.
- The statewide Trualta platform includes music and playlists with special audio technology to promote relaxation for the care receiver.
- Family Pathways facilitated a Dementia Friends session for Girl Scout Troops, utilizing the book *Grandpa and Lucy* (written by Edie Weinstein, a ninth grader from Saint Paul). Twelve girls from two different troops attended.
- The Alzheimer’s Disease and Prevention and Intervention (ADPI) grant includes funding to train Caregiver Consultants in the Music & Memory® intervention. Music & Memory® is an organization that provides personalized music training to help caregivers and care providers create individualized playlists for those living with dementia.

Recent MBA Dementia grants supported the following efforts:

- In Duluth, First Community Health Organization and The Victory Fund will expand the Victory Chorus’s educational outreach, providing social connection, musical outreach, and support networks among choir participants.
- A.C.E. of Southwest Minnesota’s project, Collaborative Connections for Memory Care Supports and Caregiver Services, provided a variety of virtual training opportunities—such as two showings of The Remember Project, a group of professional theatre artists that uses the arts to build more dementia-capable communities, a Dementia Friends training, and a Senior Life Solutions presentation.

Gaps and Opportunities to Consider

Despite the gains and progress that have been made in the past decade or so, the Alzheimer’s Disease Working Group in its 2019 report finds that Minnesota is still not fully prepared to address the impact of dementia on Minnesotans. They recommend a more comprehensive and coordinated—and less fragmented—effort that emphasizes comprehensive accountability for state actions, and prioritizing and investing in health care workforce development. Other areas for improvement include public awareness, consistency of care across residential settings, and cultural responsiveness.

Additional recommendations and opportunities include the following:

American Rescue Plan Act: Federal funding creates new opportunities

As part of the American Rescue Plan Act of 2021, a coronavirus relief bill, MBA received funds via the Administration on Community Living that can be used to invest in Title III¹⁰ program areas, including caregiving. MBA will be working with AAAs to determine how these one-time funds can be most impactfully invested; the work must be implemented over the funding period, which runs through September 2024.

Caregiver Consultants

- Build out Caregiver Consultation services, including virtual services, more broadly and consistently around the state.
- Utilize funding awarded through the Administration on Community Living (ACL) Alzheimer’s Disease and Prevention and Intervention (ADPI) grant to expand the current number of Caregiver Consultants; provide iPads/tablets to caregivers receiving Caregiver Consultation services; and train Caregiver Consultants in additional programs, such as Music & Memory®.
- Continue to invest in Trualta—the training platform that helps families build skills to manage care at home for loved ones—which Minnesota families currently can access through their work with a Caregiver Consultant.
- Explore connecting the MBA cultural consultant program to caregiver consulting. This could be a natural extension of the cultural consultants’ role and take advantage of their knowledge and existing relationships.

¹⁰ Title III of the Older Americans Act—Grants for States and Community Programs on Aging—funds supportive services (of numerous types), nutrition programs, health promotion and disease prevention services, and caregiver support.

Inclusive and equitable services

In keeping with DHS' goals to reduce disparities and institutionalize equity practices across the agency, increase focus on and investment in the following:

- Culturally competent and respectful caregiver and dementia services for Minnesotans who are Black, Indigenous, and people of color, and that reflect the nuances of different ethnicities. This includes funding and other support of culturally-specific service providers, which are often best positioned to deliver such services.
- Knowledgeable and respectful services to LGBTQ+ individuals and chosen families.

In addition, be responsive to other unique caregiving situations as they evolve, such as millennial and even Generation Z caregiving.

Hospitals and healthcare

- Establish new protocols with healthcare providers across the board to improve the discharge process so that it routinely includes training and the provision of resource information to the person who will be caregiving once home.
- Explore the possibility of rolling out Trualta through hospitals, where families could access Trualta programs before discharge to better prepare for caregiving roles at home.

Elderly Waiver

Opportunities exist to leverage the State of Minnesota's Elderly Waiver (EW) program to maximize informal caregiving. EW provides home and community-based services (HCBS) for people who need the level of care provided in a nursing home but who choose to live in the community. EW participants must be 65 or older and qualify for Medical Assistance.

- *Need for rate increases:* Demand for HCBS services will grow as the population ages, and rates paid to service providers must increase—to allow them to remain in business, pay competitive wages, and provide quality services. EW programs supplement and support the role of family and other unpaid caregivers. In 2017, 44% of EW participants received support from an informal caregiver to address one or more of their care needs. When an EW participant has the benefit of support from family and friends, the services provided through EW supplement what the caregivers can provide, and allow them to provide care longer. The EW program is designed to support the continuation of informal caregiving when possible.
- *New model:* Another model to consider is the consumer-directed community supports (CDCS) option under EW and the Alternative Care (AC) program. AC is a critical model to help address the workforce shortage. The CDCS option allows participants to hire people in their informal networks, such as family and friends, rather than rely upon a shrinking formal workforce to deliver services. It is predicted that Minnesota will be short about 60,000 direct care and support workers in the next few years. The CDCS option provides the greatest degree of flexibility for the person to purchase the services that meet their needs, while maximizing the use of informal supports.

Thank you to Minnesota's seven Area Agencies on Aging, Live Well at Home® grantees, and MBA Dementia grantees for the examples of work highlighted in this brief.