

MN
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Policy Brief: Caregiving

CAREGIVING

MINNESOTA BOARD ON AGING

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The Minnesota Board on Aging policy briefs offer an opportunity for stakeholders to learn and engage in a planning effort to reform our system and to prepare communities and the state meet the challenges and opportunities associated with an aging population.

Issue

Family and friends provide the majority of help needed by older Minnesotans to remain at home. This unpaid help is valued at \$7.9 billion a year and exceeds State Medical Assistance expenditures¹. Aging demographics coupled with longer life expectancies and increased disability rates with age will likely strain our publicly funded long-term services and supports (LTSS) system. Changing family size and composition, and increasing numbers of baby boomers who are divorced or single without children and lack traditional support networks are also factors impacting LTSS for older adults. We have an opportunity to find innovative ways to support family and friends who are vital for supporting older adults, for sustaining public funding for LTSS and lessening the impact of Minnesota's projected workforce shortage (~59,000 direct care workers by 2020)².

Current Status

In 2016, about 5 percent (27,000) of Minnesota's 585,000 caregivers were served through federal and state funded home and community-based services programs (e.g., federal Title III-E, State respite and Minnesota Board on Aging (MBA) dementia grants, Elderly Waiver, Alternative Care) and the Senior LinkAge Line®. The focus of this paper is on opportunities and recommendations for improving our state's identification and support of family and friend caregivers.

Background

Each year the MBA receives approximately \$2.1 million through the U.S. Administration on Aging for caregiver support services (Older Americans Act Title III-E funds). This funding is allocated to the Area Agencies on Aging (AAAs) that contract with local providers to deliver a range of flexible services and supports for caregivers of older adults, adults with Alzheimer's disease and grandparents raising grandchildren. It is also a catalyst for service development. This funding is targeted to caregivers of older adults with the greatest economic and social need, with particular attention to rural, low income and minority individuals. Title III-E funding supports a regional network of caregiver consultants (CCs) who offer person-centered support to family and friends including one-to-one coaching and consultation, problem solving, expertise in dementia care and family systems. Most offer Powerful Tools for Caregivers, a self-care education program for family caregivers, and REACH (Resources for Enhancing Alzheimer's Caregiver Health). Most recently REST (Respite Education and Support Tools)® is being implemented in Minnesota. Most of the providers who receive Older Americans Act Title III-E funding also serve caregivers through the other state or federally funded programs.

The MBA, in partnership with the AAAs and Twin Cities Public Television, developed *Caregiving: A Part of Our Culture*: an online series to raise awareness of caregiving and offer tips and resources for ethnic and

¹ Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain. AARP Public Policy Institute.

² MN Department of Employment and Economic Development, OES Data Tools, 2015

new immigrant caregivers. This information is translated into four languages (Somali, Spanish, Hmong and Khmer), and is available in multiple formats to organizations statewide.

In 2016, the MBA conducted a statewide evaluation of the Older Americans Act Title III-E caregiver support program through an independent contractor². This evaluation included a review of Title III-E financial and service data, key stakeholder interviews, a literature review, presentation of results and facilitated discussions. Its goal was to document the current status of the Title III-E program (how funding is being used, patterns and uptake of services to engage caregivers, gaps, successes and challenges) and how funding can be maximized to support Minnesota's caregivers.

Opportunities

Family and friend who are caregiving are increasingly diverse in terms of needs, stage of caregiving, culture, and informal support networks. Research shows that a "one size fits all" approach is not effective in supporting them. Here are examples of opportunities to support people who are caregiving based on input from key stakeholders in the recent Title III-E program evaluation:

- Addressing the unique needs of family and friends who are caregiving. Each caregiving situation is dynamic and individualistic. There is much variation in care needs, styles of caregiving, cultural norms and practices, whether the caregiver lives with, nearby or far away from the person needing care, the caregiver's own health, employment and other family roles/obligations. Minnesota's caregiver consultants are trained to offer person-centered approaches with planning and follow up for supporting the needs of each individual/family. The number of caregivers from Minnesota's cultural and ethnic communities is growing and efforts are underway to build on current successes, such as outreach partnerships, culturally specific grants and cultural consultants to advise the aging network about culturally responsive services.
- Reaching caregivers at an earlier point of need, as most seek support during crisis. It is common for family and friends to not fully realize they are "caregivers" until their loved one receives a new diagnosis, there is a change in condition or a recent discharge from a hospital, nursing facility or transitional care unit. However, reaching caregivers earlier can reduce stress and improve confidence and care skills. Examples of earlier intervention include information and education about a disease/condition, skills training to perform care tasks, holding family meetings to plan ahead and support the primary caregiver, and finding respite and other community resources.
- Improving caregiver health by strengthening informal support networks. Caregiving can be rewarding and offer satisfaction, personal growth and increased meaning and purpose in one's life. However, caregivers may be reluctant to accept support from others (both unpaid and paid) due to a variety of factors and end up "doing it all", sometimes at a personal cost (physical, emotional and financial). A recent Minnesota study³ found that family and friend caregivers who have strong informal support networks had better self-reported health and less frequently described their roles as "very stressful". Another role of Minnesota's caregiver consultants is to assist family and friends

² Minnesota Title III-E Caregiver Program Evaluation. Amherst H. Wilder Foundation. 2017.
<http://www.wilder.org/Wilder-Research/Publications/Pages/results-Older-Adults.aspx>

³ Understanding Caregivers' Networks of Support. Amherst H. Wilder Foundation. 2012.

to identify informal support networks to assist them with caregiving and develop a plan for moving forward.

- Replicating best practice models and evidence-based interventions to fill gaps in service. As the demand for unpaid caregivers grows the aging network is seeking innovative ways to support family and friends caregiving. This includes partnerships with health care providers, businesses, and working more closely with other service providers to increase capacity to support caregivers. Other opportunities include leveraging online education resources, chat and market-based solutions to support caregivers.
- Seeking new partnerships and innovations to support caregivers in crisis. There is currently limited capacity for crisis response. The aging network is looking for ways to support those in crisis by exploring ways to increase aging network capacity to respond to crisis, develop referral protocols to agencies and organizations with 24 hour helplines (e.g., Alzheimer’s Association, Suicide Prevention hotline), offer online chat, and developing partnerships around creative solutions.
- The 2017 Minnesota Legislature authorized the MBA to re-establish a time-limited Alzheimer’s Disease Working Group to review and revise the 2011 report, “Preparing Minnesota for Alzheimer’s: the Budgetary, Social and Personal Impacts.” The recommendations from this group, which will be presented to the 2019 Legislature, will guide future efforts to support people with Alzheimer’s disease and related dementias and their family/friend caregivers.

Recommendations for Strategic Priorities

1. Continue/increase support for caregivers of older adults during transitions of care, and others who are stressed and at risk of formal placement of older adults⁴. Increase partnerships with clinics, hospitals and health care homes (HCHs), and coordination with Senior LinkAge Line® to identify and support family caregivers. Continue/increase support for family caregivers including those caring for adults with Alzheimer’s disease, rural, low income and culturally diverse caregivers and others as per the Older Americans Act.
2. Increase coordination between Senior LinkAge Line® and caregiver services grantees to maximize support for caregivers through calls and Return to Community (RTC) Expansion. Beginning July 2019, a new caregiving service component will be launched that offers self-directed budgets for family and friends of certain individuals enrolled in the RTC program. This is an opportunity to test new ways of supporting family and friend caregivers in a more targeted, flexible and coordinated way.
3. Revamp messaging and service delivery models geared to family and friend caregivers. Take a holistic approach of supporting caregivers and care receivers at the same time. Consider addressing the care receiver’s needs first as families and friends may reach out for help during crisis or transitions of care. For example, caregivers may be more willing to take some help if it is geared towards the care receiver (and also provides them with a break, respite). Create easy and practical service “on ramps” as initial forms of support for caregivers, including transportation, meals, chore services, or housekeeping help. Educate family and friend caregivers about LTSS options in an effort to divert/delay use of assisted living and facility-based care.

⁴ Spillman, B., Long, S.K., *Does High Caregiver Stress Lead to Nursing Home Entry?* Urban Institute, 2007.

4. Increase availability of affordable respite including in-home, out-of-home, self-directed and culturally specific options. Consider offering a range of respite options including volunteer and fee for-service models. Refer to the most recent DHS Gaps Analysis for identified gaps in respite. Think more broadly about services that offer a respite outcome such as adult day services, companion, chore or homemaker.
5. Increase work with cultural and ethnic communities to develop models that best meet the needs and preferences of those in their community who are providing care as well as the care receivers. These efforts must include workforce development (staff training and employing staff from the same cultural or ethnic community), consultation with cultural consultants about policy and service development and making information available in a variety of formats and languages. Build on successes such as ACT on Alzheimer's dementia friendly communities, REACH (Resources for Enhancing Alzheimer's Caregiver Health) Community, and *Caregiving: A Part of Our Culture*, a cultural caregiving awareness and education program developed by the MBA with AAAs and Twin Cities Public Television.
6. Expand the caregiver consultation service and create regional "hubs" or virtual centers to increase access to a range of support for people who are caregiving. Examples might include online education, consultation, finding and using technology, family meetings and chat. Ensure that staff at service hubs is empowered to be early access and referral points for caregivers. Review current state, regional and local policy and guidelines to increase flexibility and accessibility to support and engage more caregivers, including those from cultural and ethnic communities. Streamline contracting and paperwork burden for self-directed services and providers of service.
7. Train caregiver consultants to assist family and friends with finding/using various technologies to complement their roles and ease care tasks. Examples include online calendars, virtual visits, mobile apps and assistive technology.
8. Explore/promote market-based solutions for supporting caregivers. Includes vouchers for services and supports and better technology to support older adults and caregivers. Package services and supports in ways that appeal to caregivers and health care providers.
9. Raise employers' awareness of caregiving and older workers to promote workplace flexibility through business leaders and key partners as a way to improve workplace environments and lessen workforce shortages. This also makes good business sense as supporting employee caregivers is shown to enhance productivity, lower absenteeism, improve worker retention and provides a competitive edge in recruiting high quality employees.
10. Establish measureable outcomes for the programs seeking to support family caregivers. Explore methods to document return on investment for caregiver support services as a way to generate state funding in order to sustain capacity.