A Study of Title III-E Caregiver Services in Minnesota

Where are we now and where could we go next?

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Prepared by: Christin Lindberg and Greg Owen

451 Lexington Parkway North | Saint Paul, Minnesota 55104
651-280-2700 | www.wilderresearch.org

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Introduction

The current unprecedented growth of America's older adult population has created both opportunities and challenges. Among the opportunities is the growing recognition by many elders that there are hundreds of ways to give back to their communities through voluntary service on their own or through charitable organizations. And Minnesota is clearly a leader in this arena. (http://www.mncompass.org/aging/volunteerism#1-4365-g) But among the challenges is the expectation for many, that there is now, or soon will be, a need for them to step into the role of caregiver for a family member or friend.

With or without the "caregiver" label, this role has been assumed for centuries, probably for as long as social bonds have existed among humans. But the population shift we are experiencing now has brought these care needs into sharper focus, and with this, more substantial and sustained attention to the range of tasks and demands that go with the role of non-paid caregiver.

The study is a response to a request from the Minnesota Board on Aging to explore how available funds for caregivers have been spent and what caregivers, service providers, and aging experts say about current and future needs and services. Specifically, the report explores how federal and state resources made available through Title III-E of the Older Americans Act have been configured, offered, and used in Minnesota and what might be done to optimize the value of these resources in the future.

Background

In 2000, the Administration on Aging established the National Family Caregiver Support Program (NFCSP), which provides grants for supports for informal and family caregivers to provide care for older adults that will allow them to remain in their homes for as long as possible. Funding, provided through Title III-E of the Older Americans Act, is "designed to build an integrated caregiver service system that supports and empowers family and informal caregivers; provides diverse and flexible service options to address caregivers' individual needs and preferences; reduce caregiver burden; and extend the time that care can be provided at home."[1] Other federal and state aging grants and waivers also support caregivers.

The NFCSP provides five types of services:

- Information about services and supports
- Assistance in finding and accessing services
- Individual counseling and coaching, support groups, and caregiver training
- Respite care
- Supplemental services

Eligibility requirements[2] for care recipients include:

- 60 years of age or older,
- Or, any age, with Alzheimer's disease or related dementias

Special consideration is given to caregivers of older adults with the greatest social and economic needs.

The background and characteristics of caregivers are well-documented. In Minnesota, for example, an estimated 1 in 6 people aged 18 and older provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. The estimated annual value of the care and assistance provided by informal family and friend caregivers in Minnesota is $7.86 billion,[3] which exceeds Medicaid expenditures for nursing homes and long-term services and supports.[4]

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[1] Retrieved from: http://mnraaa.org/serviceproviders/2017_titleiiie_application/

[2] Some NFCSP funding may be used to support older relative caregivers providing care for a grandchild, a relative's child or an adult child with a disability. Supports for caregivers to these care recipients are not the focus of this report.

[3] Retrieved from http://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html

[4] Retrieved from http://www.mn.gov/dhs Family Caregivers fact sheet

The impact of the stress and burden of caregiving on caregivers is also well-documented. Caregivers have higher levels of depression and are twice as likely to experience chronic illness. They may also face negative consequences through economic hardships, impact on work schedules, and isolation. Many caregivers say that they need supports to perform and sustain this caregiving, and assessments and programs have been created to supplement the care they provide.

While the benefits of interventions for caregivers' well-being have also been extensively documented (Gitlin et al, 2015; Sörenson et al, 2002), what has remained more difficult to discern is how to reach stressed and burdened caregivers with the services that have been created to help. Many informal caregivers do not self-identify as caregivers, and may also be reluctant to accept supports. In fact, many caregivers are also less likely to pro-actively seek supports, waiting instead to seek help only when a crisis arises. For many, caregiving is often "just what you do" for a family member, not a special role or unique responsibility.

Minnesota has been at the forefront of initiatives to reach and serve caregivers. Keeping caregivers healthy is imperative if older adults are to be able to remain in their homes for as long as they wish, and out of more restrictive settings.

In 2016, the Minnesota Board on Aging contracted with Wilder Research to complete a study on the current availability and use of Title III-E caregiving services. The study was designed to answer the following questions:

- How is Title III-E funding currently used in each AAA region? How are funds distributed across the various caregiver service grantees and how is the funding being used?
- What services do MN caregivers currently use and how well do Title III-E funds support their needs?
- What does a review of existing literature reveal about the support needs of caregivers in MN?
- What service models have been used to engage and serve caregivers? What patterns are seen in the uptake of services by consumers?
- What changes or innovations should be reflected in the next 3 year State Plan to best serve the future needs of caregivers and they people they care for?

Data sources and methods

The following activities were completed in order to answer the evaluation questions:

- Review of state data, provided by the MBA and MN Department of Human Services
- Focus group and pencil-and-paper questionnaire with Area Agency on Aging representatives
- Interviews with key experts and stakeholders
- Literature review and annotated bibliography, including a review of recent Minnesota initiatives and studies on caregiving

Minnesota caregiver data

Staff from MN DHS provided aggregated Title III-E data to Wilder for analysis. Data for 2013, 2014 and 2015 include:

- Numbers of unduplicated caregivers, including by Area Agency on Aging
- Funding, including by Area Agency on Aging
- Types of services received
- Characteristics of Title III-E caregivers
- Numbers and types of grantees for Title III-E
- MBA Caregiver Outcomes Survey data
- NFCSP activities timeline

Complete results are located in Appendix A. Definitions of the Title III-E services are located in Appendix B.

Interviews with AAA representatives

The Area Agencies on Aging group members were given two opportunities to respond to a series of questions. Questions included the strengths and challenges related to current Title III-E caregiver services, characteristics of successful providers, current funding strategies, needs for information about caregivers, and expectations for this study. The group discussed their responses to these questions as they relate to Title III-E caregiving services at a meeting in May, 2016, and then were asked to respond to the questions in writing. The complete list of questions is located in Appendix F.

Literature review and review of current Minnesota studies

Wilder Research completed an extensive review of current literature. The keyword and phrase search included the following terms and concepts:

- family caregivers
- caregiver burden
- supporting and engaging caregivers
- barriers to caregivers getting and accepting help
- interventions with caregivers
- what caregivers think they need and want
- what caregivers find helpful
- differences in caregivers' needs (health concern of care recipient, rural vs. urban, gender, race, age, etc.).
- current delivery models for home care, community-based services, respite care

The MN information includes recent studies and reports related to the availability of services and supports for informal caregivers, as well as their needs for and use of services and supports.

Descriptions of programs currently used in Minnesota are located in Appendix C. The annotated bibliography is located in Appendix D. The summary of current MN studies related to caregiving is located in Appendix E. The list of references is located in Appendix I.

Interviews

Wilder completed semi-structured telephone interviews with 21 individuals in October, 2016. The key informants were initially selected by DHS, based on their knowledge and experience with caregiving, including policy perspectives and practical applications. The reach of the key informants was expanded based on their recommendations of additional respondents who could provide unique perspectives on the evaluation questions for this study. Two potential provider respondents declined to participate.

Respondents included:

- 11 providers of caregiver services
- 4 AAA staff members from Minnesota
- 3 policy strategists and experts from outside Minnesota
- 2 subject matter experts in Minnesota
- 1 AAA staff member from another state

The content of the interviews varied based on respondents' position or organization and knowledge of Title III-E funding. Background information provided to respondents included basic funding trends, and the interviews focused on their policy and/or direct service perspectives. Questions included current Title III-E funding priorities and implementation, caregivers' awareness of services, engagement with caregivers, barriers experienced by caregivers in accessing services, and effectiveness of programs and services. The complete list of questions is located in Appendix H.

Findings

Summary of Minnesota caregiver data

Title III-E funding

Since 2000, when NFCSP funding was first authorized, Minnesota has engaged in extensive caregiver services development activities, including legislative, program, and training or outreach initiatives. A complete timeline of achievements in located in Appendix A.

A variety of key program activities helped to set the course for caregivers in MN, beginning in 2004. Highlights include developing caregiver coaching (2004), routinely using the Live Well at Home™ Rapid Screen (2007) for risk assessment, developing Family Memory Care (2007), initiating ACT on Alzheimer's with a broad focus on the needs of those caring for individuals with memory loss (2009), implementing the Powerful Tools for Caregivers pilot (2012), implementing TCARE® (Tailored Caregiver Assessment and Referral) (2013), and developing the community pilot for REACH (2014) and REST (Respite Education and Support Tools) in 2016. Other innovative programs developed through Live Well at Home grants include Caregiver Café, PS I Understand, Mobile Outreach, as well as several partnerships with health plans and primary care clinics to engage family caregivers through referrals and support. Training and education highlights include launching the caregiver awareness campaign (2004) and culturally relevant outreach regarding caregivers and dementia (beginning in 2014), with the first cohort of cultural consultants trained in dementia care in 2016.

In Minnesota, Title III-E funds support family caregivers through six service categories, including information services; access assistance; individual counseling, support groups, and caregiver training; respite care; supplemental services; and self-directed service grants.

Title III-E funding has declined slightly between 2013 and 2015, but has provided services for increasing numbers of family caregivers. Figure 1 below shows statewide totals. Figure A2 in Appendix A provides further detail by AAA.

1. MN Title III-E expenditures and caregivers served -- totals

Year	2013	2014	2015
Funds	$1,480,869	$1,341,717	$1,281,847
Caregivers Served	3372	3747	4364

Note. Number of caregivers served is across all services.

Figure 1 reflects expenditures and caregivers served for OAA registered services such as caregiver coaching and counseling, respite care and supplemental services but does not include information services, access assistance, some caregiver training and support services, Grandparents Raising Grandchildren grants, or the Minnesota Indian Area Agency on Aging. The Senior LinkAge Line® also serves many caregivers each year.

The AARP Public Policy Institute (2015) estimated that 585,000 caregivers provided unpaid care to an adult in Minnesota in 2013. The number of caregivers served by Title III-E funding is a small fraction of the number of caregivers—less than 1% in 2013. However, it is noteworthy that caregivers received 64,269 units of respite and 20,684 units of caregiver coaching provided through Title II-E funding in 2015.

Most characteristics of caregivers served by Title III-E funding in MN have remained largely consistent during the three years for which data are available. (Figures A6a-A6d in Appendix A provide full details about the characteristics of Title III-E caregivers.)

The following characteristics define the typical Title III-E caregivers (based on 2015 data):

- About three-quarters (77%) are female
- Most are White (86%)
- Fourteen percent of caregivers served are from non-White ethnic and racial groups.[5] Six percent are Asian, 4% are Black, 3% are White Hispanic, and less than 1% are American Indian, Native Hawaiian or other Pacific Islander, or mixed race[6]
- Three percent are Hispanic or Latino
- About 70% are under 74 years of age (31% under 60 and 40% are 60-74 years). Just under thirty percent are age 75 and over, including 21 percent who are age 75-84 and 7% who are 85 and over
- The majority of caregivers served (72%) are at or below 200% of poverty. One quarter are below 100% of poverty

Between 2013 and 2015, proportions for some characteristics changed, including the following:

- The number of Title III-E caregivers who live with others has increased (73% in 2013, 77% in 2014, and 80% in 2015)

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[5] Some caregivers are under age 60.

[6] 6.1% of adults age 60+ in MN are people of color (2013), although caregiver status of these adults is unknown. [Source: https://agid.acl.gov/]

- The number of caregivers served in rural areas has decreased (57% in 2013, 55% in 2014, and 50% in 2015)

The numbers of grantees receiving Title III-E funding in 2016 vary by AAA location and types of services provided. Overall, 50 agencies were awarded grants. Thirty-one agencies provided individual counseling and 31 provided respite. Twenty-four agencies provided group counseling. Complete Title III-E data are located in Figures A2 through A7 in Appendix A.

In addition to the six regional Area Agencies on Aging, the Minnesota Indian Area Agency on Aging (MIAAA) receives a small Title III-E grant used primarily to support Grand Kin (grandparents raising grandchildren) on Leech Lake, White Earth, Bois Forte, and Grand Portage reservations. The MIAAA also operates a licensed native adult day center and receives Older Americans Act Title VI funding for Native American Caregiver Support Services for services such as access assistance, counseling, support groups and respite.

MBA caregiver outcomes survey

The Minnesota Board on Aging conducts an annual survey of caregivers served through Title III-E funded programs. The survey is completed through the AAAs and is used to obtain demographic data and feedback on the services received. Over three years, caregivers gave high marks to the Title III-E services they received. The majority of respondents said that the services helped them cope better, improved their ability to provide care, and helped them provide care for longer. See Figure 2 (below). Figure A12 in Appendix A shows detailed results of these three survey questions.

2. MBA Caregiver outcomes survey (2013-2015)

	N=3323
Percent of caregivers reporting that Title III-E services helped them cope better	98%
Percent of caregivers reporting that Title III-E services improved their ability to provide care	95%
Percent of caregivers reporting that Title III-E services helped them provide care longer or much longer	95%

Source. MBA Caregiver Outcomes Survey data, collected by Area Agencies on Aging.

Non-Title III-E funding

Beyond Title III-E funding, caregivers may also receive support from Alternative Care, Elderly Waiver, and state funded Live Well at Home grants. DHS staff report that use of respite care has declined over the past three years, while use of adult day services has increased. Staff hypothesize that family caregivers may benefit from the respite provided by services such as adult day, companion, and chore or homemaker.[7] Figures A8 through A12 in Appendix A provide additional details about funding outside of Title III-E.

Alternative Care and Elderly Waiver funding

Alternative Care (AC)[8] and Elderly Waiver (EW)[9] fund services that may be used by caregivers. Both funding sources provide HCBS for low income older adults who are eligible for nursing home care, based on the level of care they require, but who choose to live in a community setting. Elderly Waiver eligible older adults qualify for Medical Assistance; Alternative Care eligible older adults do not qualify for Medical Assistance, but must be low income and unable to afford more than 135 days of nursing home care and have no other means to pay.

Services covered under these funding sources include respite care, family caregiver services, and adult day services. Expenditures for MN Alternative Care and the two Elderly Waiver options for respite care and caregiver services have decreased from 2013 to 2015. Expenditures for adult day services have increased over the same time period. See Figure 3. (This figure is also located in Appendix A as Figure A8.)

3. MN Alternative Care, Elderly Waiver-Fee for Service, Elderly Waiver-Managed Care Organizations funding for family caregivers (in thousands)

Service type	2013 Expenditure	2014 Expenditure	2015 Expenditure
Respite Care Services	$618,527	$582,956	$422,664
Family Caregiver Services	$3,573	$1,798	$1,058
Adult Day Services	$28,274,762	$31,242,440	$35,164,899

Notes. Expenditures are estimates based on units of service multiplied by rates or sum reimbursements. Figures have been rounded to the nearest whole dollar amount.

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[7] Information provided by DHS staff, August, 2016.

[8] The Alternative Care (AC)--Retrieved from https://mn.gov/dhs/people-we-serve/seniors/services/home-community/programs-and-services/alternative-care.jsp

[9] The Elderly Waiver (EW)--Retrieved from https://mn.gov/dhs/people-we-serve/seniors/services/home-community/programs-and-services/elderly-waiver.jsp

Figure 3 indicates that adult day service programs are of growing importance within the Elderly Waiver and Alternative Care programs. Adult day service programs are an important source of support for family caregivers. They are also used to meet other needs of participants, and are not limited to caregiver support needs. However, the increase in spending on adult day services suggests that the adult day service model, which benefits both the care recipient and the caregiver, is a particularly attractive type of support. This is consistent with other findings about caregivers that suggest caregivers often respond best to supports that are initiated, at least partly, in response to the care needs of their care recipient.

Live Well at Home grants

Another source of funding for caregiver supports and respite are Live Well at Home grants. These grants are intended to fund innovation in service delivery for older adults and family caregivers, and may provide additional funding for services that offer a respite "outcome", such as adult day health and companion services.[10]

From 2014 to 2016, the grant funding for the support of caregiver innovations increased from $454,000 to $478,000. The numbers of caregivers served through Live Well at Home grants increased from 299 in 2014, to 2,759 in 2015, and leveled off in 2016. (See Figures A9-A11 in Appendix A.) See Figure 4.

4. Minnesota Live Well at Home grants

	2014	2015	2016
Grant funding	$454,000	$479,000	$478,000
Caregivers served	299	2,759	2,693
Impressions from social media campaign	103.4 M		

Figure 4 shows a significant variation in the numbers of caregivers served from 2014 to 2015. The bulk of the investment in 2014 went to a multi-media caregiver awareness campaign (print, digital, social media, outdoors, and radio) that resulted in $103.4 million impressions (views) from family caregivers.

The Live Well at Home Rapid Screen© is integrated into all Live Well at Home grants. Live Well at Home grant funding has also been used to open several adult day centers in rural communities, including the first tribal adult day program in Minnesota, as well as flexible respite models and other innovative programs such as P.S. I Understand (a mentoring program that matches new and experienced caregivers).

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[10] Information provided by DHS staff. Source: email from August 11, 2016.

MBA Dementia Grants

In 2015, the MN Board on Aging also awarded state funding for dementia grants to support older adults with dementia and family caregivers in an amount of $750,000. This effort has also lead to the development of cultural consultants to assist aging network and health care providers to offer more culturally responsive services to Minnesota's ethnic and culturally diverse communities. Figure 5 shows the funding and numbers of caregivers served in 2015 and 2016. (See Figures A9 and A10 in Appendix A.)

5. Minnesota Board on Aging dementia grants

	2015	2016
Grant funding	$750,000	$750,000
Caregivers served	225	225

Summary of observations from Area Agency on Aging representatives

In May, 2016, AAA staff participated in a group discussion and completed written responses to the same questions. They identified the following strengths of current efforts to reach caregivers, barriers and key challenges to providing sufficient services for caregivers, and recommendations for actions that could improve services. The questions are included in Appendix F.

Strengths of current caregiver services

AAA staff mentioned the following strengths of current caregiver services:

- Title III-E funding provides the backbone of funding and allows for a range of services to be available.
- Powerful Tools for Caregivers has value as an on-ramp for caregiver identification.
- Best to offer a range of options for respite that include both volunteer and fee-for-service models (Note: some blended models have been offered by providers under contract with AAAs.).
- Useful to focus on service packages, diverse offerings that can be tailored to the caregivers' needs.
- It is essential to create trusting relationships.
- Strong asset is the professionalism and passion of provider staff.

Barriers and key challenges to providing caregiver services

AAA staff offered the following observations about barriers and key challenges:

- Inadequate long-term funding/insufficient funding to cover underserved communities.
- Lack of providers and providers lack capacity.
- Rural service areas offer no economies of scale.
- Different counties and different caregivers have unique needs.
- Limited capacity for crisis response.

Recommendations/opportunities

AAA staff offered the following thoughts on opportunities that may support program development and offerings for caregivers:

- Create referral sources with medical systems.
- Develop an accounting of all caregiver supports and services offered and used (beyond just Title III-E) in order to determine true scale of need.
- Respond to what caregivers say they actually need and will use.
- Create additional opportunities for discussions with other AAAs and providers to share information about best practices.
- Attract providers by offering more flexible and attractive Title III funding.

Summary of findings from literature review and current studies

Wilder completed an extensive review of literature and compiled both a an annotated bibliography of 32 of the most relevant research reports (located in Appendix D) and list of references (located in Appendix I). In addition, Wilder summarized recent studies and reports on caregiving, specific to Minnesota (located in Appendix E).

Literature review

A comprehensive review of the findings from the literature has revealed the following key themes:

- Caregiving situations are unique and complex, and change over time.[11]
- Caregivers need flexible, customized options for support; one size does not fit all.[12]
- Caregivers need options for support that reflect cultural differences.[13]
- Caregivers and care recipients should be considered and treated as a unit, including documenting the caregivers on medical records.[14]
- Many caregivers put the needs of their care recipients first.[15]
- Inroads can be made in reaching caregivers by building a relationship and trust.[16]
- Interactive partnerships with an interdisciplinary team may provide the most comprehensive and flexible supports.[17]
- There is a need for strategies to address systems barriers, such as a fragmented and often difficult to navigate HCBS system, affordability of services and supports, and current practices that provide prescriptive information and guidance about services.[18]

In addition, the National Academy of Sciences report, Families Caring for an Aging America, calls for a shift from person-centered care to person- and family-centered care, as well as the development and implementation of a national strategy that includes:

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[11] Boots et al, 2015; Friedemann et al, 2014; Herrera et al, 2013; Lévesque et al, 2010; Lopez Hartmann et al, 2012; McCabe et al, 2016; National Academy of Sciences, 2016; National Caregiver Alliance, 2016; Phillipson et al, 2014; Wennberg et al, 2015

[12] Boots et al, 2015; Brookman et al, 2011; Hong, 2010; Lopez Hartmann et al, 2012; Lilly et al, 2012; Masters, 2006; McCabe et al, 2016; Mittelman & Bartels, 2014; Montoro-Rodriguez et al, 2003; Phillipson et al, 2013; Robinson et al, 2013; Samia et al, 2012; Stern Center for Evidence-Based Policy, 2016; Stirling et al, 2010; Warrick et al, 2014

[13] Casado et al, 2011; Friedemann et al, 2014; Herrera et al, 2013; Hong, 2010; Montoro-Rodriguez et al, 2003; National Academy of Sciences, 2016; Reinhard & Choula, 2012; Scharlach et al, 2006; Wennberg et al, 2015

[14] Jensen & Inker, 2015; Kelly et al, 2013; Martindale-Adams et al, 2015; Mast, 2013; Mintz, 2013; National Academy of Sciences, 2016; Reinhard & Choula, 2012; Scharlach et al, 2006; Warrick et al, 2014; Wennberg et al, 2015

[15] Friedemann et al, 2014; Lilly et al, 2012; Mast, 2013; National Caregiver Alliance, 2016; Phillipson et al, 2013; Stockwell-Smith, 2010

[16] Lévesque et al, 2010; Mast, 2013

[17] Jensen & Inker, 2015; Kelly et al, 2013; Lévesque et al, 2010; Lopez Hartmann et al, 2012; Qualls, 2016; Wennberg et al, 2015

[18] Casado et al, 2011; Hong, 2010; Mast, 2013; National Academy of Sciences, 2016; Phillipson et al, 2014; Qualls, 2016; Stern Center for Evidence-Based Policy, 2016; Stockwell-Smith et al, 2010

- “Effective mechanisms to ensure that family caregivers are routinely identified in delivery of services to older adults with impairments
- Medicare and Medicaid payment reform to motivate health care providers to engage family caregivers effectively
- Training of health care and long-term services and supports providers to engage caregivers
- Dissemination and funding for evidence-based caregiver services
- Evaluation and adoption of federal policies that provide economic support to working caregivers
- Expansion of the national data collection infrastructure to create a knowledge base about caregivers” (p.3).

Detailed summaries of key research studies are located in Appendix D.

Studies in Minnesota

Caregivers to Older Adults

The results from the 2013 Caregivers to Older Adults study (Wilder Research) are particularly relevant to the evaluation questions posed by DHS for the Title III-E Caregivers Study. In 2013, more than 100 caregivers in the Twin Cities metropolitan area participated in 13 focus groups to discuss their experiences. The study was designed to answer the following main questions:

- Why do caregivers not take advantage of existing caregiver support services?
- To what extent does the current array of caregiver support services represent a “good fit” with the actual needs and conditions of caregivers?

Barriers mentioned by caregivers that prevent them from taking advantage of existing supports include:

- Lack of awareness of services
- Concerns about the quality of services
- Care receivers’ resistance to using services
- Cost of services and lack of clarity about which services a caregiver might be eligible to receive
- Reliance on informal support from family, friends, and non-relatives

- Failure to recognize the need for help
- Difficulty finding sources of useful information
- Need for supports that meet cultural needs and expectations

Caregivers reported making connections to services through a random process of gathering information, or based on specific needs at the time. They also accessed services in a crisis situation, or when outside help was required to meet the care recipients' needs.

Caregivers believed they would benefit from the following supports:

- Easy access to information
- Opportunities to connect with others for support and education
- In-home and community-based services that are practical, flexible, trustworthy, reliable, consistent, and affordable
- Additional formal and informal services that offer daytime and overnight respite, transportation assistance
- Workplace supports
- Availability of culturally relevant services in those communities

Recommendations based on the findings included:

- Begin with the assumption that every first door should be the right door for a caregiver to begin accessing support.
- Create opportunities for contact with experienced caregivers.
- Take advantage of the fact that caregivers put their care recipient first. This could mean offering supports to caregivers based on what they need to provide helpful care to their care recipients.
- Provide caregiver education to middle-aged (and older) adults in multiple settings.
- Make workplace education and attention to the needs of caregivers the norm and not the exception.
- Make early identification of needs and opportunities for joint caregiver/care recipient participation a focus of services to caregivers serving those with memory loss.

- Consider the application of evidence-based programs that use behavioral activation as a strategy for reducing depression and stress among caregivers.

Caregiving in Context

Wilder completed the Caregiving in Context study in 2012, which included in-depth telephone interviews with 141 primary caregivers randomly selected from seven St. Paul neighborhoods. Although not generalizable to all communities, the results are instructive about how caregivers might be expected to seek and engage supports that are useful to them.

These results indicate the significant weight caregivers place on the opinions of both family members and friends, as well as their own health care providers when it comes to both information and support. These results also suggest that caregivers most often take advantage of practical supports that can meaningfully ease the day to day burden of caregiving.

- The top five places caregivers say they would look for information are medical sources, the internet or websites, case manager or social worker, county or state social services, and community-based organizations.

- The top six types of home-based services caregivers reported using in the past month include assistance from an organization or business, nursing care from a home health aide, transportation or rides, personal care from a home health aide, home delivered meals, and housekeeping help.

- The top seven types of help caregivers reported receiving from other individuals include basic assistance from family members, friends or neighbors; heavy chores; transportation or rides; housekeeping help; correspondence or paperwork; shopping help; and managing finances.

- The top three most important resources caregivers reported currently having in place to support them in their role include support from family members, friends, and others; health care resources; and home-based services.

Complete data tables are located in the summary for this study in Appendix E, Figures E1-E4.

Additional Minnesota studies

Findings from additional current research and studies in Minnesota reflect the perspectives of caregivers, as well as advocates or providers. These studies are reviewed in detail in Appendix E. Taken in sum, the studies indicate that the supports that caregivers believe will be most helpful include:

- Flexible and trustworthy services, including respite

- Multiple options for accessing information
- Connections with others for support and education, including peer support
- Services that are accessible in non-urban locations
- Supports that reflect cultural differences and the unique circumstances of each caregiver

Components that advocates believe will help caregivers:

- Access to one point of contact and information before a crisis
- Coordinated systems, including health care system attention to caregivers
- Building trust with caregivers to reduce their resistance to accepting help
- Improved reimbursement rates and funding streams
- Policies that support recruiting and retaining providers, including improved reimbursement rates and engagement strategies that help produce a more consistent demand for services
- Continued and ongoing education for caregivers about caregiving and available services
- Continued and ongoing education for providers to implement early interventions

Summary of findings from key informant interviews

In fall, 2016, Wilder completed semi-structured telephone interviews with 21 key informants in Minnesota and in other locations in the United States. Key informants were asked to share their policy and/or direct service perspectives. Questions included current Title III-E funding priorities and implementation, caregivers' awareness of services, engagement with caregivers, barriers experienced by caregivers in accessing services, and effectiveness of programs and services. The interview guide is included in Appendix H. Additional comments that illustrate the perspectives of the respondents are located in Appendix G.

Respondents included:

- 11 providers of caregiver services
- 4 AAA staff members from Minnesota
- 3 policy strategists and experts from outside Minnesota
- 2 subject matter experts in Minnesota
- 1 AAA staff member from another state

Respondent experience with caregiving

Key informants were asked to indicate the areas in which they have current caregiver experience. They most commonly identified experience with caregiver program planning and development (mentioned by 18), and caregiver program management (mentioned by 13), as well their personal role as an unpaid caregiver (mentioned by 12).

AAA staff perspectives on Title III-E funding

MN DHS staff recommended that Wilder interview four Area Agency on Aging staff regarding Title III-E funded services and use of self-directed grants.

Use of current Title III-E funds

Three of the four respondents believe that Minnesota is using current funds in a way that best achieves the goal of Title III-E programs. Although they see constant need for improvement, they also believe that their AAAs offer a variety of services for individuals' needs, and that they are doing good work.

Respondents also believe that the Older American Act guidelines for using funds could be more flexible. For example, promoting the caregivers' needs related to the care recipient (e.g., homemaker or transportation) with a family-centered focus would benefit everyone. Paperwork and funding requirements for providers can be burdensome and further reduce access to the Title III-E funds that can offer significant supports. Other forces, beyond the funds, related to volunteer recruitment and retention, caregiver consultant capacity, and caregivers' continued lack of uptake on services have hindered full use of Title III-E funds.

Improving the use of these funds has been an ongoing issue, according to the AAA respondents. They suggested such measures as reducing the administrative burden of the provider contracts, using Title III-B funds to support care coordination, elevating the importance of the role of caregivers via health care professionals and other key community contacts, and improving flexibility in responding to caregivers' changing needs as ways to more fully use available funds.

Self-directed grants

Area Agencies on Aging currently offer a limited number of Title III self-directed grants of funding to high-risk family caregivers for the purchase of goods or services, or to hire and manage their own workers. AAAs screen caregivers, determine the amount of the grant, and work with caregivers to develop plans. Grants are currently used for respite, meals, transportation, and other services. Self-directed grants offer flexibility, choice and control to individuals. A fiscal support entity provides assistance in managing the budget and financial functions, including assuring compliance with IRS and other federal laws and requirements.[19] According to the MBA, "the self-directed services delivery model allows access to Title III funds for hiring workers and buying agency-based services and goods. Through an assigned budget amount and guidelines established in this policy, eligible individuals may directly purchase services and supports to address identified needs and/or risk factors. Primarily, SDS funds shall be used for paying workers that support the individual's ability to live in the community. Funds may also be used to purchase agency-based and vendor services and goods."[20]

All respondents said that their AAAs currently provide self-directed grants, some on a limited basis. Families do find value in the flexibility, but the cost share and funding caps can create additional challenges. Forms and administrative rules, and making the arrangements are an additional burden to caregivers. Two respondents mentioned expanding the reach of self-directed grants by using Title III-B funds for care coordination or consultation.

Respondents believe it may be worthwhile to explore the use of self-directed grants at transition points. Addressing the needs of the care recipients and successfully identifying the high-risk caregivers are critical functions. The perspective of one respondent is reflected in a quotation located in Appendix G.

Caregivers' awareness of and access to services

The following topics were addressed by all respondents.

While caregivers' awareness may be increasing, respondents believe that levels of awareness leading to service engagement are nevertheless quite limited. The reasons cited by respondents for this lack of awareness are varied. In particular, family members may not view themselves as caregivers or they may not understand that services even exist.

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[19] Information provided by MBA staff, August, 2016.

[20] Retrieved from http://www.mnlivewellathome.org/en/Professional%20Toolkit/~/media/lwah/prof-toolkit-program-manual-forms/SelfDirected%20Services%20Policy%20FINAL%20effective%20031811.ashx

For those caregivers who have some awareness and ability to seek supports, respondents believe that they do manage to connect to services. Even so, an awareness of services does not automatically mean that caregivers will access these services, although there are many factors that determine access. Respondents remarked that younger caregivers or those who are already on other forms of public assistance may have a better grasp of using services. However, caregivers may also be reluctant or have trouble navigating the system. Additional comments are located in Appendix G.

Ideas for improving awareness and access to services

Respondents acknowledge that finding the caregivers and building awareness is an ongoing task. Going to where the caregivers are, rather than waiting for caregivers to come to providers is key. Suggestions include activities (educational events, presentations, and community workshops), locations (faith communities, pharmacies, grocery stores, libraries, and community centers, workplace settings), public service messages broadcast through social and print media[21], education print materials, and contact with health care providers or other community members.

A number of respondents cautioned that it is important to begin with an understanding of the needs of caregivers, and recognition that they start their caregiving journeys at different points, in different ways. Building trust and a personal connection is also important. Additional comments are located in Appendix G.

Addressing resistance to accepting help

Caregivers have personal and varied reasons for resisting support. A sense of obligation to the care recipient, being overwhelmed and avoiding one more thing, a lack of trust in health care or other systems, cost concerns, the wrong kind of assistance being offered, or services offered at the wrong time, can all lead caregivers to resist help. Respondents offered three main types of suggestions for addressing resistance, including building relationships with caregivers, reframing the offer of help, and determining what supports caregivers actually want. Additional comments are located in Appendix G.

Types of help that make the most difference for caregivers

Respondents were nearly unanimous in talking about how one size does not fit all for supporting caregivers. What caregivers need can be determined by the unique family relationships, disease trajectory, and characteristics and situation of the caregivers and care recipients.

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[21] A number of respondents specifically highlighted the work by Wilder Foundation and MN DHS for the "We Call It Caregiving" public awareness campaign. Further information on this work is located in Appendix E.

Respondents also mentioned many times the importance of personal connections with peers and coaches, and through support groups.

Other types of help mentioned by respondents include a long list of practical supports including respite, homemaker and chore assistance, home care and hospice, and household management.

Additional comments are located in Appendix G.

Examples of effective programs or service models

Respondents mentioned a number of evidence-based programs and assessments that they believe are particularly effective, including Family Memory Care (*NYUCI*), *Live Well at Home Risk Assessment*, *Powerful Tools for Caregivers*, *REACH*, *Paths to Faithful Caregiving*, and *Memory Club*. These programs are described in more detail in Appendix C.

Key informants shared information about innovative programs within Minnesota, that are not evidence-based, but which seem to be meeting the needs of informal family caregivers. Programs include a variety of respite options including paid respite, *Morning Out* respite, and *The Gathering*; as well as non-respite programs such as *Saturday Connections* (for caregivers and care receivers together), and in-home *Exercise Buddies*.

Also mentioned were a number of unique programs and interventions, implemented outside of Minnesota, including *Caring for You; Caring for Me*, *Issues and Management of Caregiving*, *Operation Family Caregiver*, and *Benjamin Rose Institute (BRI) Care Consultation.*

In addition to describing specific programs and mentioning programs by name (both evidence-based and non-evidence-based), key informants shared a number of observations about the qualities that make programs particularly effective. Responses ranged from descriptions of a multi-component focus, one-on-one formats, and supports for diverse communities.

Key informants were also asked about caregivers' access to self-directed services. They like the idea or principle of self-directed services, but acknowledge that it is not a perfect solution. While families who have used this assistance have largely benefited from customized services and are satisfied, the system remains difficult to navigate.

Addressing caregivers' barriers for getting services

Key informants most often mentioned a lack of awareness of the services themselves, a lack of identification as a caregiver (by self and others), finances, and being overwhelmed by the need to balance caregiving and other responsibilities, as the main barriers faced by caregivers.

Key informants also shared opinions about what could be done to reduce the barriers. Responses included varied efforts to shift awareness in communities with broader educational efforts, improvements in technology, implicating health care providers in fostering connections with caregivers, and adjusting reimbursements. Additional comments are located in Appendix G.

Additional observations and issues to consider

Key informants shared a broad variety of useful observations and suggestions for future considerations. Topics covered include systems issues, funding concerns, and caregivers' needs. Representative comments are located in Appendix G.

Summary observations and considerations

The information presented in this report provides a picture of caregiver needs, current services, and potential opportunities for strengthening both the engagement of caregivers and the improvement of current service strategies. The following observations and considerations are intended to summarize both the learnings from this study and potential directions for future action.

1. **How is Title III-E funding currently used in each AAA region? How are funds distributed across the various caregiver service grantees and how is the funding being used?**

Based on three years of funding data reviewed for this study, total funds distributed for Title III-E services decreased from $1.48 to $1.28 million from 2013 to 2015. Over this same time period however, the total number of people served increased from approximately 3,400 to 4,400 across all regions of the state. Title III-E dollars distributed to AAAs appears to follow a distribution pattern reasonably proportional to the population of each AAA region.

The vast majority of those served during the most recent period for which data is available (2015) were White women at or below 200% of poverty. According to service records, most received access assistance, caregiver counseling, coaching or a related form of support. Slightly less than one-quarter of service recipients received respite care.

Title III-E services are currently reaching less than 1% of Minnesota caregivers. However, caregivers received 64,269 units of service for respite and 20,864 units of service for caregiver coaching through Title III-E funding in 2015.

2. **What services do MN caregivers currently use and how well do Title III-E funds support their needs?**

The most recent in-depth assessment of caregiver needs among a random community sample of those caring for older adults in St. Paul, MN (Wilder Research, 2012) showed that support by family and friends was identified as the most important form of caregiver support by over 60% of all study respondents (N=141). Nonetheless, many caregivers also identified the support of health care professionals (48%) or home or community based services (23%) as "…one of the most important resources in place to support [my] role as a caregiver."

Among those using home based services and supports, nursing services involving medications, dressing changes, or treatments were used by the largest percent of caregivers (25%), followed by transportation services (17%), home health aide services to meet ADL needs of the care recipient (16%), home delivered meals and housekeeping assistance (15% each), help with heavy chores (7%), shopping and use of adult day health programs (5% each), meal preparation (4%), and help with paperwork or respite care (3% each). These findings suggest that there are more opportunities to reach caregivers using Title III-E funding if awareness of and connections to these services can be improved.

3. What does a review of existing literature reveal about the support needs of caregivers in MN?

An extensive review of current literature, and findings from studies completed in Minnesota identified a wide-ranging list of needs for caregivers. According to literature and research, caregivers in Minnesota would benefit from services that:

- Consider their unique needs and circumstances, including the family unit and diverse cultural needs
- Acknowledge the role of the caregiver as an essential team member (including within the healthcare system)
- Accommodate changing needs over time, according to the disease trajectory
- Provide coordinated referral and payment systems that simplify and streamline access
- Include trusting relationships with providers and access to the expertise of other caregivers
- Provide multiple options for access to information, including access through health care providers, places of employment, and through ongoing public awareness and marketing.
- Offer trustworthy and reliable assistance
- Support caregiving in the workplace

4. What service models have been used to engage and serve caregivers? What patterns are seen in the uptake of services by consumers? (What does the study tell us about what caregivers need and want from others? What have we learned about how best to offer and organize supports for caregivers?)

Evidence-based programs such as Powerful Tools for Caregivers, REACH Community, and Family Memory Care received high marks from experts interviewed for this study. Beyond the actual programs referenced, however, we have learned that caregivers may benefit most from service models with the following characteristics and components:

- Opportunities for the early identification of caregivers, such as when a caregiver's care recipient experiences a health transition; such as at the time of a significant change in functional status, a new diagnosis, or other significant change in health status
- Outreach and marketing in all Minnesota communities to promote ongoing awareness of caregiving and available supports
- Outreach and education for health professionals who often have the opportunity for initial contact with caregivers
- Workplace education and supports for employed caregivers
- Assessments that identify customized support options based on individual needs
- Contacts and connections that build trust over time and remain available until caregivers feel ready to seek some form of support
- Comprehensive programs that provide options and accommodate the unique needs of caregivers, care recipients, and family relationships
- Simplified paperwork and clear payment requirements
- Support to manage complex medical issues and comorbid conditions

For a variety of reasons ranging from a general lack of awareness of services to variations in individual circumstances, caregivers' uptake of services can be unpredictable. We have learned that caregivers may be more likely to take advantage of practical supports that address the day to day burden of caregiving. They are also more likely to turn to family and friends or known and trusted service providers in the event of a crisis or a sudden change in condition. Thus, caregivers can benefit when knowledge of supports for caregivers is widely known and shared. Caregivers also benefit from high quality and reliable services that are flexible enough to address their unique and changing needs.

5. **What changes or innovations should be reflected in the next 3 year State Plan to best serve the future needs of caregivers and they people they care for? (What could be done to expand the reach and benefit of Title III-E programs?)**

This study has surfaced a wide range of observations about caregivers and their needs, along with facts and opinions regarding the current configuration and use of Title III-E services. The following ideas are offered for consideration by both planners and service providers as potential avenues to explore in developing the next iteration of Title III-E funding priorities and service offerings:

Systems and policy considerations

1. Find ways to increase AAA and caregiver service grantee partnerships with clinics, hospitals, and health care homes for the purpose of identifying and referring caregivers to support services.

2. Review provider reimbursement levels to those organizations receiving grants under AAA contract to provide Title III-E and related services.

3. Create easy and practical service "on ramps" as initial forms of support for caregivers, including transportation, meals, chore services, or housekeeping help. For example, leverage other Title III, state and federal grant funded programs. Ensure that service areas are educated and empowered to be an early access point for caregivers. workers in these

4. Consider ways to increase availability of flexible respite options for caregivers and address gaps in respite based on the most recent Gaps Analysis report.

5. Increase flexibility and accessibility of programs to engage more caregivers. This could include a review of policy, standards, and guidelines, as well as current engagement strategies and service offerings. Identify the extent to which they meet both person-centered and self-directed support criteria.

6. Identify ways to reduce paperwork burden for self-directed services and providers of service.

7. Review current Medicare and Medicaid benefits to identify opportunities to improve the support these programs can offer to caregivers.

8. Create a governor's task force for aging that includes a focus on caregivers with an ongoing focus on what various agencies of state government can do to strengthen support for caregivers.

9. Increase Title III support for organizations that can bring caregiver education to the workplace. Identify two or three corporate champions to demonstrate this kind of support for caregivers in the workplace.

Caregiver support strategy considerations

10. Identify strategies to help consumers better understand the potential cost of caregiver services and what they would be expected to pay for them.

11. Highlight/enhance current efforts of Senior LinkAge Line® to engage caregivers through calls and program initiatives.

12. Consider the creation of local or regional call-in support groups for caregivers using existing Title III-E funding. Focus services on those who find it difficult to leave their home and the person for whom they are caring. Periodic phone conferencing could be used for support, information exchange, problem solving, and as an on-ramp to other services.

13. Consider a review and identification of monitoring or sensing technology that can be especially useful to caregivers. Provide coaching and training on the use of technologies that are demonstrated to be helpful to caregivers in supporting the needs of their care recipients.

14. Establish benchmarks or measures for caregiver support services to determine effectiveness.

Outreach strategy considerations

15. Develop video explanations of caregiver supports and services, and testimonials by caregivers who have used the services for use on MinnesotaHelp.info®, and through other web portals or public information sites that caregivers may access.

16. Create a quarterly or semiannual caregiver service provider forum, either through face-to-face meetings rotating to various locations around the state, or through interactive television or webinars, intended to highlight current practices and provide an opportunity for discussion and brainstorming among providers.

17. Reactivate the statewide caregiver awareness campaign with new messages and strategies derived from this review and related work.

18. Ask Senators Franken and Klobuchar to consider recording website or PSA messages about the ways in which caregivers can benefit from services provided under Title III-E and related funding streams.

19. Expand/continue efforts to educate employers about workplace flexibility and resources for employee caregivers.

Appendix A: Minnesota caregiver data

A1. Caregiver services development timeline

Year	Legislative/Funding Milestone	Program Milestone	Education/Training/ Outreach Milestone
2000	OAA Title III-E NFCSP funding authorized First federal Alzheimer's grant	Companionship respite and mobile adult day model	
2001	MBA Title III-E NFCSP policy approved AAAs develop and begin to award caregiving grants		
2002		MBA-DHS Caregiving Summit	As Families Grow Older training
2003			*Making the Link,* an outreach campaign for physicians
2004		Caregiver Coaching developed	ECHO/TPT Caregiving awareness
2005		Caregiver Coaching developed	Caregiving awareness at public transit stops
2006	Title III-E CDCS Family Adult Day approved for EW/AC	Powerful Tools for Caregivers	Care Well campaign
2007		LWAH Rapid Screen™ TCARE® and Family Memory Care development Transform 2010/AAA/EDP partnerships	Working Caregiver Initiative
2008	Title III-E Grandparents grants		Caregiver Coaching family meeting skills training
2009		ACT on Alzheimer's	FMC Physician/clinic outreach
2010			Caregiver Coaching curriculum revised
2011			Advanced Dementia Capability training
2012		MBA Caregiver Resource booklet and guide Memory Care Support Group and Memory Café	Powerful Tools for Caregivers pilot Standardized assessment & skills training

Source. MN Board on Aging staff, August 2016

A1. Caregiver services development timeline (continued)

Year	Legislative/Funding Milestone	Program Milestone	Education/Training/ Outreach Milestone
2012		MBA Caregiver Resource booklet and guide Memory Care Support Group and Memory Café	Powerful Tools for Caregivers pilot Standardized assessment & skills training
2013	New HCPC and billing rates for EW/AC Family Caregiver Service	TCARE® Implementation evaluation	Inside the Family Circle: Mastering the Family Meeting
2014	Extended State Family Medical Leave	MN Choices Caregiver Questionnaire for all waivers REACH Community pilot	What is a Caregiver? Campaign Cultural Awareness in Dementia Care video series
2015	FMC eligibility beyond spouses FMC added to EW/AC waivers	REACH Community pilot	Caregiver awareness campaign for new ethnic immigrant families
2016	CARE Act MBA Dementia grants awarded	REST Program Evaluation of NFCSP and SOM Caregiver Brief	Advanced Dementia Capability & Caregiver Coaching training on- line First cohort of cultural consultants trained in dementia awareness

Source. MN Board on Aging staff, August 2016

Title III-E funding

A2. Title III-E caregivers served and costs by AAA and year

		AAAA	CMCOA	LDSAAA	MAAAA	MNRAAA	SEMAAA	Total
2013	# Title III-E caregivers served (unduplicated)	460	615	447	1,212	446	192	**3,372**
	Total Title III-E $$$	$165,167	$274,712	$215,245	$598,868	$174,006	$52,871	**$1,480,869**
2014	# Title III-E caregivers served (unduplicated)	428	630	480	1,552	468	189	**3,747**
	Total Title III-E $$$	$206,092	$316,315	$190,884	$410,450	$167,880	$50,096	**$1,341,717**
2015	# Title III-E caregivers served (unduplicated)	399	683	940	1,684	467	191	**4,364**
	Total Title III-E $$$	$173,214	$252,530	$215,245	$437,131	$152,090	$51,637	**$1,281,847**
2016	# Title III-E caregivers served (unduplicated)	354	595	921	1706	444	215	**4,235**
	Total Title III-E $$$	--	--	--	--	--	--	**--**

Note. Does not include figures for access assistance and information services data, or statewide caregiver education and awareness, or grandparents caregiving grants. Does not include data from the Minnesota Indian AAA. 2016 expenditures not yet available.

A3a. Unduplicated number of Title III clients for caregiver counseling (NAPIS service type) by AAA

	AAAA	CMCOA	LDSAAA	MAAAA	MNRAAA	SEMAAA	Total
2013	403	612	537	891	419	174	**3,036**
2014	363	612	315	1,056	441	179	**2,966**
2015	329	641	437	1,011	452	182	**3,052**

A3b. Unduplicated number of Title III clients for respite care (NAPIS service type) by AAA

	AAAA	CMCOA	LDSAAA	MAAAA	MNRAAA	SEMAAA	Total
2013	159	102	120	257	63	110	**811**
2014	145	109	125	305	70	86	**840**
2015	119	122	133	299	75	103	**851**

A3c. Unduplicated number of Title III clients served

NAPIS service type	2013	2014	2015
Caregiver Counseling - Individual/Family	3,036	2,966	3,052
Respite	811	840	851

Note. Does not include data on clients served for access assistance, information services, caregiver training or support groups, grandparents caregiving grants, or data from the Minnesota Indian AAA.

A4. Title III Access Assistance and Information Services Expenditures

	2013	2014	2015	2016
Access Assistance	$234,459	$265,472	$270,939	$273,019
Information Services	$72,015	$47,738	$86,675	$80,513

A5. Federal Labor-HHS Appropriations (in thousands) for Title III-E[22]

	2010	2013	2014	2015	2016	2017
Title III-E Family Caregivers Support	$154,220	$145,586	$145,586	$145,586	$150,586	$150,911

Source. National Association of Area Agencies on Aging

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[22] National figures only. Not available for MN.

A6a. Demographic characteristics of Title III-E caregivers by AAA for 2013

	AAAA	CMCOA	LDSAAA	MAAA	MNRAAA	SEMAAA	Total	
Age							**N=3,365**	
Under 60	138	190	85	556	98	47	**1,114**	**33%**
60 - 74	185	235	225	395	177	90	**1,307**	**39%**
75 - 84	106	146	97	190	114	36	**689**	**20%**
85+	31	42	38	70	57	17	**255**	**8%**
Rural							**N=3,179**	
Yes	368	562	389	22	415	71	**1,827**	**57%**
No	53	39	12	1,109	18	121	**1,352**	**43%**
Gender							**N=3,318**	
Female	327	439	319	909	330	142	**2,466**	**74%**
Male	120	165	116	291	110	50	**852**	**26%**
Lives with							**N=1,329**	
Alone	38	92	46	88	87	11	**362**	**27%**
With others	78	285	130	313	126	35	**967**	**73%**
Poverty level							**N=1,033**	
100 (<=100)	20	84	18	80	34	6	**242**	**23%**
150 (101-150)	41	87	51	65	47	8	**299**	**29%**
200 (151-200)	25	65	34	40	30	10	**204**	**20%**
NA (>200)	41	62	38	92	39	16	**288**	**28%**
Race							**N=3,214**	
2 or more races	2	1	0	2	0	0	**5**	**<1%**
American Indian/ Alaskan Native	9	3	6	4	2	0	**24**	**<1%**
Asian	1	1	1	214	0	1	**218**	**7%**
Black or African American	1	0	1	80	0	1	**83**	**3%**
Native Hawaiian/ Other Pacific Islander	1	0	0	2	0	0	**3**	**<1%**
Other race	2	2	0	11	2	3	**20**	**<1%**
White Hispanic	4	3	5	75	7	4	**98**	**3%**
White not Hispanic	413	572	371	794	431	182	**2,763**	**86%**
Ethnicity							**N=3,098**	
Hispanic/Latino	4	4	6	85	3	5	**107**	**3%**
Not Hispanic/Latino	398	568	351	1,104	384	186	**2,991**	**97%**

A6b. Demographic characteristics of Title III-E caregivers by AAA for 2014

	AAAA	CMCOA	LDSAAA	MAAA	MNRAAA	SEMAAA	Total	
Age							**N=3,740**	
Under 60	130	182	114	650	109	37	**1,222**	**33%**
60 - 74	174	257	236	547	184	86	**1,484**	**40%**
75 - 84	83	150	94	271	116	47	**761**	**20%**
85+	41	39	35	80	59	19	**273**	**7%**
Rural							**N=3,558**	
Yes	343	588	445	40	451	76	**1,943**	**55%**
No	47	26	11	1,408	10	113	**1,615**	**45%**
Gender							**N=3,624**	
Female	292	464	332	1,156	369	135	**2,748**	**76%**
Male	123	156	138	314	91	54	**876**	**24%**
Lives with							**N=1,826**	
Alone	41	98	47	107	116	14	**423**	**23%**
With others	94	333	226	545	160	72	**1,403**	**77%**
Poverty level							**N=1,507**	
100 (<=100)	38	118	56	119	61	13	**374**	**25%**
150 (101-150)	23	83	66	98	44	19	**405**	**27%**
200 (151-200)	40	95	72	108	52	28	**333**	**22%**
NA (>200)	38	118	56	119	61	13	**395**	**26%**
Race							**N=3,552**	
2 or more races	1	0	0	0	0	0	**1**	**<1%**
American Indian/ Alaskan Native	4	3	11	10	2	0	**30**	**1%**
Asian	2	1	0	259	0	0	**262**	**7%**
Black or African American	0	1	0	121	0	3	**125**	**4%**
Native Hawaiian/ Other Pacific Islander	1	0	0	4	0	0	**5**	**<1%**
Other race	0	0	0	6	2	4	**12**	**<1%**
White Hispanic	3	6	10	98	9	4	**130**	**4%**
White not Hispanic	382	600	421	970	437	177	**2,987**	**84%**
Ethnicity							**N=3,451**	
Hispanic/Latino	4	4	11	103	7	6	**135**	**4%**
Not Hispanic/Latino	368	599	415	1,366	387	181	**3,316**	**96%**

A6c. Demographic characteristics of Title III-E caregivers by AAA for 2015

	AAAA	CMCOA	LDSAAA	MAAA	MNRAAA	SEMAAA	Total	
Age							**N=3,755**	
Under 60	95	182	78	672	87	55	**1,169**	**31%**
60 - 74	180	257	186	629	190	76	**1,518**	**40%**
75 - 84	85	150	89	301	136	40	**801**	**21%**
85+	39	39	33	82	54	20	**267**	**7%**
Rural							**N=3,636**	
Yes	284	588	371	69	437	66	**1,815**	**50%**
No	98	26	8	1,553	11	125	**1,821**	**50%**
Gender							**N=3,591**	
Female	279	464	282	1,235	367	138	**2,765**	**77%**
Male	115	156	100	322	80	53	**826**	**23%**
Lives with							**N=1,928**	
Alone	34	98	41	91	108	4	**376**	**19%**
With others	109	333	225	635	177	73	**1,552**	**80%**
Poverty level							**N=1,593**	
100 (<=100)	15	134	23	155	60	6	**393**	**25%**
150 (101-150)	28	118	64	128	72	13	**423**	**27%**
200 (151-200)	23	83	67	103	43	16	**335**	**21%**
NA (>200)	43	95	86	123	60	35	**442**	**28%**
Race							**N=3,604**	
2 or more races	0	0	0	8	0	3	**11**	**<1%**
American Indian/ Alaskan Native	4	3	10	4	1	0	**22**	**<1%**
Asian	0	1	1	220	0	0	**222**	**6%**
Black or African American	0	1	0	145	0	1	**147**	**4%**
Native Hawaiian/ Other Pacific Islander	0	0	0	5	0	0	**5**	**<1%**
Other race	1	0	0	6	2	4	**13**	**<1%**
White Hispanic	1	6	5	78	2	2	**94**	**3%**
White not Hispanic	380	600	359	1,132	439	180	**3,090**	**86%**
Ethnicity							**N=3,512**	
Hispanic/Latino	2	4	5	81	2	3	**97**	**3%**
Not Hispanic/Latino	370	599	363	1,502	393	188	**3,415**	**97%**

A6d. Demographic characteristics of Title III-E caregivers - combined

	2013		2014		2015	
Age	**N=3,365**		**N=3,740**		**N=3,755**	
Under 60	1,114	33%	1,222	33%	1,169	31%
60 - 74	1,307	39%	1,484	40%	1,518	40%
75 - 84	689	20%	761	20%	801	21%
85+	255	8%	273	7%	267	7%
Rural	**N=3,179**		**N=3,558**		**N=3,636**	
Yes	1,827	57%	1,943	55%	1,815	50%
No	1,352	43%	1,615	45%	1,821	50%
Gender	**N=3,318**		**N=3,624**		**N=3,591**	
Female	2,466	74%	2,748	76%	2,765	77%
Male	852	26%	876	24%	826	23%
Lives with	**N=1,329**		**N=1,826**		**N=1,928**	
Alone	362	27%	423	23%	376	19%
With others	967	73%	1,403	77%	1,552	80%
Poverty level	**N=1,033**		**N=1,507**		**N=1,593**	
100 (<=100)	242	23%	374	25%	393	25%
150 (101-150)	299	29%	405	27%	423	27%
200 (151-200)	204	20%	333	22%	335	21%
NA (>200)	288	28%	395	26%	442	28%
Race	**N=3,214**		**N=3,552**		**N=3,604**	
2 or more races	5	<1%	1	<1%	11	<1%
American Indian/Alaskan Native	24	<1%	30	1%	22	<1%
Asian	218	7%	262	7%	222	6%
Black or African American	83	3%	125	4%	147	4%
Native Hawaiian/Other Pacific Islander	3	<1%	5	<1%	5	<1%
Other race	20	<1%	12	<1%	13	<1%
White Hispanic	98	3%	130	4%	94	3%
White not Hispanic	2,763	86%	2,987	84%	3,090	86%
Ethnicity	**N=3,098**		**N=3,451**		**N=3,512**	
Hispanic/Latino	107	3%	135	4%	97	3%
Not Hispanic/Latino	2,991	97%	3,316	96%	3,415	97%

A7. Title III-E grantees 2016

Area Agency on Aging	Number of III-E grantees	Number of grantees providing individual counseling	Number of grantees providing group counseling	Number of grantees providing respite	Number of grants awarded
AAAA	11	8	1	7	11
CMCOA	8	5	5	6	7
LDSAAA	5	4	3	4	5
MAAA	10	8	8	7	10
MNRAAA	5	3	4	4	5
SEMAAA	10	3	3	3	10

A8. MN Alternative Care, Elderly Waiver-Fee for Service, Elderly Waiver-Managed care organizations funding for family caregivers (in thousands)

Service type	2013 Expenditure	2014 Expenditure	2015 Expenditure
Respite Care Services	$618,527	$582,956	$422,664
Family Caregiver Services	$3,573	$1,798	$1,058
Adult Day Services	$28,274,762	$31,242,440	$35,164,899

Note. Expenditures are estimates based on units of service multiplied by rates or sum reimbursements
Note. Figures have been rounded to the nearest whole dollar amount

A9. Additional funding sources for Minnesota

Source	2014	2015	2016
Live Well at Home grants (respite/caregiver support)	$454,000	$479,000	$478,000
MBA dementia grants	--	$750,000	$750,000

A10. Minnesota Live Well at Home and dementia grants caregivers served[23]

Source	2014	2015	2016
Live Well at Home grants	299	2,759	2,693
MBA dementia grants	--	225	225

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[23] The variation in numbers of caregivers served is due to changes in the providers and work that can change from year to year.

A11. Impressions from the Wilder Foundation's What is a Caregiver? campaign

Media type	Number of impressions
Print	.35 M
Digital	51 M
Social	2.2 M
Outdoors (billboard and transit)	46.9 M
Radio	3 M
Total	**103.4 M**

Source. MBA staff

A12. MBA Caregiver (CG) Outcomes Survey data

	2013 (N = 1248)	2014 (N= 926)	2015 (N=1149)
% of CGs reporting that Title III-E services helped them cope better	98%	98%	97%
% of CGs reporting that Title III-E services improved their ability to provide care	96%	95%	95%
% of CGs reporting that Title III-E services helped them provide care longer or much longer	95%	95%	95%

Source. MN Area Agencies on Aging and Title III-E providers

Appendix B: Definitions

Note: Unless otherwise noted, definitions excerpted from MN Board on Aging documents.

Title III funding allocations

Allocations for each AAA are based on the intrastate funding formula and approval of area plans. AAAs use their allocations according to regional needs assessments and planning for caregiver services under the Older Americans Act. While some providers may offer multiple services, those services may be funded as one grant.[24]

Counseling

Services under this category assist family caregivers in making decisions and solving problems related to their caregiving roles. This includes: individual or family counseling, coaching, support groups, training and education, and self-directed support services. These services may be provided in person, by telephone, or via the internet depending on the needs of the caregivers.

Respite care

Respite care services offer temporary, substitute care, supervision, support, or living arrangements to older persons in order to provide a brief period of relief or rest for information caregivers. Services include in-home, out-of-home, facility-based, or self-directed respite.

Supplemental services

These services are provided on a limited basis to ease the burden of care or to complement the care provided by caregivers. This includes: home modifications and technology, miscellaneous services, and self-directed services. (Note: Funding limited to no more than 20% of Title III-E allocation).

Access assistance

Access assistance can be an adjunct to caregiver training and education.[25] This service assists caregivers in obtaining access to available services and resources within their communities. To the maximum extent practicable, it ensures that the individuals receive the services by establishing adequate follow-up procedures.

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[24] Email from MBA staff, November, 2016.

[25] Ibid.

Information services

These services provide the public and individuals with information about available resources and services statewide. Note: services…are for activities directed at large audiences of current or potential caregivers (e.g., large group sessions, distribution of consumer materials, media campaigns, caregiver fairs or conferences.)

Title III-E "set-aside" grant is considered Information Services and is up to 5% of the total Title III-E allocation. This grant is used to increase capacity for professionals supporting caregivers to broaden awareness of caregiving, and link caregivers with information and support.[26]

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[26] Email from MBA staff, November, 2016.

Appendix C: Descriptions of programs and assessments

Descriptions of the evidence-based or evidence-informed programs and assessments either mentioned by respondents as particularly effective or included in reference material follow.

Family Memory Care (NYUCI)

Source:
http://www.dhs.state.mn.us/main/groups/publications/documents/pub/dhs16_198588.pdf

“Family Memory Care Intervention (FMC) is a coaching and counseling service [used in Minnesota] to support family caregivers of persons with Alzheimer’s disease and related dementias. The goal of FMC is to improve the ability of caregivers who live with a person with dementia (PWD) to withstand the difficulties of caregiving by improving social support and minimizing family conflict. FMC is a translation of the evidence-based New York University Caregiver Intervention (NYUCI) developed by Dr. Mary Mittelman and colleagues at the NYU Alzheimer’s Disease Center (Mittelman, Roth, Clay, and Haley, 2007).”

“FMC outcomes to be achieved:

- Reduced negative impact of caregiving behaviors
- Decreased symptoms of depression
- Enhanced support network composition and effectiveness
- Delay or prevent institutionalization of the person with Alzheimer’s disease“

“FMC Components:

- Two individual sessions with the primary caregiver. An initial session to assess needs and strengths, develop a care plan and plan for the first family meeting, and a final session following the family meetings.
- Four family sessions within the first four months
- Ad hoc counseling to offer support and resources for at least 12 months
- Follow up assessments every 6 months following the family meetings”

Live Well at Home^{SM} risk assessment

Source:
http://www.mnlivewellathome.org/Professional%20Toolkit/~/media/lwah/prof-toolkit-program-manual-forms/SCREENING%20Description.ashx

The Live Well at Home Rapid Screen© is an easy-to-administer7-question tool to help older adults and/or family caregivers identify personal risks most often associated with nursing home admission and/or spend down to Medical Assistance. The screening process also includes a short education session about what's important about the risks, ideas on how to manage risks, and services and supports for mitigating risks.

The Live Well at Home Rapid Screen© is a validated evidence-informed tool. It consists of seven questions taken from high quality research on the factors most predictive of permanent nursing home and/or assisted living placement that are most amenable to risk mitigation. The questions address assistance with daily activities, injurious falls, has family member/friend available for help, stressed caregiver, considering a move and lives alone. Two additional questions address memory concerns observed by the screener, and income of the older adult.

The Live at Home Rapid Screen© was developed by the Minnesota Board on Aging in 2009 under a grant from the Administration on Aging, and in partnership with the Arrowhead Area Agency on Aging, Central Minnesota Council on Aging, and the Minnesota River Area Agency on Aging. The University of Minnesota conducted the research, design, and evaluation activities for the tool.

The screen is used statewide and in partnership with Minnesota's Area Agencies on Aging.

Memory Club

Source:
http://www.alz.org/mnnd/documents/16_ALZ_Memory_Club_Flyer.pdf

Memory Club is a program for people with memory loss and their care partners, and is designed to meet the needs of both members of the dyad. The program offers a total of 10 sessions. The first half of each session is used to cover topics relevant to care partners and the people with memory loss. For the second half of each session, care partners meet together and people with memory loss meet together to share unique experiences and discuss topics of interest.

Paths to Faithful Caregiving

Source:
http://www.ageoptions.org/documents/PathstoFaithfulCaregivingdraftbrochure9-25-14.pdf

Created by AgeOptions, “this program combines traditional stress management and communication skills with exercises that help caregivers brainstorm how their faith communities and practices can help them with caregiving difficulties… It has been tested in urban and suburban settings with a diverse range of caregivers from various faith backgrounds.”

Powerful Tools for Caregivers®

Source: MBA staff. See also http://www.powerfultoolsforcaregivers.org/

“Powerful Tools for Caregivers® is an education program to help family and friends caring for older adults with long-term health conditions (e.g., stroke, Alzheimer’s, Parkinson’s disease, and others).”

“Powerful Tools helps caregivers develop skills and confidence to better care for themselves while caring for others. It is a six-week series led by trained facilitators using a standardized curriculum. The weekly topics range from reducing your stress to communicating in challenging situation and mastering caregiving decisions.”

REACH Community

Source: MBA staff. See also https://www.uthsc.edu/prevmed/memphis-caregiver-center/

The REACH (Resources Enhancing Alzheimer’s Caregiver Health) Community is a proven approach to support family members and others who are caring for someone with Alzheimer’s disease or a related dementia. Based on 20 years of research and clinical translation, REACH has been shown to decrease burden, depressive symptoms, the number of troubling dementia-related behaviors reported, and potential for abuse as measured by caregiver frustrations. The goal is to teach caregivers how to reduce stress, solve problems and manage difficult behaviors the person with memory loss may display, as well as help caregivers feel confident in the care they provide and improve their ability to cope. Four core sessions are tailored to the caregiver’s unique situation based on the major areas of risk identified through the Risk Priority Inventory. The inventory covers: health/physical well-being, social supports, frustrations and vigilance, well-being and mood. Care recipient’s cognition, safety and behavioral symptoms are also covered. Sessions can be conducted face-to-face (home or office) or be telephone. A 2 – 3 month time period is a common timeframe for the intervention. Additional sessions are offered based on the needs/desire or the caregiver.

REST® (Respite Education and Support Tools) Program

Source: MBA staff. See also: http://restprogram.org/

Minnesota is implementing the REST® Program, a national training program that provides skills and tools needed to provide quality respite. Respite, or short-term temporary relief, supports caregivers who are caring for loved ones. Respite allows caregivers to step away from their duties to refresh and recharge.

REST® is a train-the-trainer course that prepares individuals to conduct respite training, equipping REST® Companions to provide respite in order to support caregivers who are caring for people with disabilities and healthcare needs across the lifespan. The goal of REST® is to deliver education and support to those offering a break to caregivers.

Appendix D: Annotated bibliography

Boots, L., Wolfs, C., Verhey, F., Kempen, G., and de Vujt, M. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: The paradox between needing and accepting help. *International Psychogeriatrics, 27*(6), 927–936. http://doi.org/10.1017/S1041610214002804

The authors discussed four themes in the experiences of caregivers. *Early-stage needs paradox*: In spite of the potential helpfulness of information, early-stage caregivers struggle to accept help, resist the stigma of dementia, and find that early information has a largely negative focus. *Barriers in acceptance*: When caregivers struggle to accept the disease and experience negative emotions in relation to the disease, their abilities to seek or accept assistance is further compounded. *Facilitators in acceptance*: Specific knowledge about the disease, established structures and routines, and acknowledgement of the impact of the disease on roles/relationships helped to reduce the negative impact of the disease. *Transition from loss to adaptation*: A focus on possibilities improved the ability of caregivers to adapt their expectations. The trajectory of adjustment to the disease is unique for each caregiver, and is influenced by characteristics of the pre-diagnosis relationship. Interventions must be customized for each caregiver, and must consider that the ability to articulate a subjective burden (emotional perception of the caregiving responsibilities) precedes adaptation, and may not translate to specific actions. This research was completed in the Netherlands.

Brookman, C., Holyoke, P., Toscan, J., Bender, D., and Tapping, E. (2011). ***Promising practices and indicators for caregiver education and support programs.*** Markham, ON: Saint Elizabeth Research Department.

Researchers completed a review of current research on effective programs for caregivers in Canada. They identified the following promising practices and indicators:

Promising practices	Promising practices indicators
#1 Respond to the unique care situation	Ask caregivers what they need; tailor services and content accordingly
	Consider the relationship between the caregiver and care recipient
	Include strategies to address family dynamics and roles
	Consider the influence of gender
	Recognize cultural influences
#2 Stimulate caregiver involvement and interest	Foster networking among caregivers
	Make connections to community services
	Offer online interactive program components
	Help caregivers apply knowledge and skills

Promising practices	Promising practices indicators
#3 Address the emotional context of providing care	Reinforce that caregivers need to care for themselves
	Recognize the different emotional stages of caregiving
	Affirm caregiver competence and confidence
	Encourage caregivers to consider their positive experiences
#4 Provide relevant information	Educate caregivers about how the system works
	Provide practical strategies for caring
	Address informational needs over time
#5 Enable caregiver participation	Arrange for respite if needed
	Arrange for transportation if needed
	Make the program convenient
	Provide a welcoming and comfortable atmosphere

Casado, B. L., van Vulpen, K. S., & Davis, S. L. (2011). Unmet needs for home and community-based services among frail older Americans and their caregivers. *Journal of Aging and Health*, *23*(3), 529–553. http://doi.org/10.1177/0898264310387132.

In their study of unmet needs for HCBS, the authors identified 5 key reasons that caregivers are not using services:

- Lack of awareness of the service
- Reluctance for having other people in the home
- Unavailability of a service
- Affordability of a service

The authors concluded that African American older adults appear to be at greatest risk for unmet needs, due to health literacy and disparities in access to services. The authors also suggest that additional research could guide the development of services that appropriately target older adults.

Friedemann, M-L, Newman, F.L., Buckwalter, K.C. & Montgomery, R.J.V. (2014). Resource need and use of multiethnic caregivers of elders in their homes. *Journal of Advanced Nursing*, *70*(3), 662-673.

This article presents results of multi-cultural research completed to assess the barriers experienced by caregivers to using services that support them in their roles. The most important factor in encouraging caregivers to seek supports was the needs of the care recipients, regardless of cultural beliefs and perception of need. The authors suggest that assessing the needs of caregivers on an individual or family basis is the key to acknowledging common values, recognizing unique caregiving situations, and avoiding assumptions about cultural groups.

Herrera, A. P., George, R., Angel, J. L., Markides, K., & Torres-Gil, F. (2013). Variation in Older Americans Act Caregiver Service Use, Unmet Hours of Care, and Independence Among Hispanics, African Americans, and Whites. *Home Health Care Services Quarterly*, *32*(1), 35–56.

The numbers of older adults of color are increasing and one size does not fit all in access or use of HCBS. Language barriers and lower health literacy for minority caregivers may prevent them from accessing services. The authors suggest that older adults may benefit from a wider array of culturally specific services that address their unique health care needs.

Hong, S.-I. (2010). Understanding Patterns of Service Utilization Among Informal Caregivers of Community Older Adults. *Gerontologist*, *50*(1), 87–99.

The author assessed caregivers' support networks and use of HCBS through the lens of the Andersen model and Network Episode Model. Key findings include the following:

- Caregivers' use of services is varied and distinct
- The HCBS system is fragmented and navigation is a challenge for caregivers
- Family and other informal relationship configurations influence the use of HCBS
- Caregivers receive instrumental support and information through social supports
- Middle-income caregivers are caught between Medicaid eligibility and affordability of private-pay services, which may reduce their ability to access services
- Race affects service needs and use

Jensen, C.J. & Inker, J. (2015). Strengthening the dementia care triad: Identifying knowledge gaps and linking to resources. *American Journal of Alzheimer's Disease & Other Dementias*, *30*(3), 268-275.

This article highlights the importance of the relationship between the medical provider, caregiver, and care recipient. Care recipients benefit when their caregivers have access to information about the disease and treatment options, as well as available supports. Medical staff are better able to provide care when they have accurate information and referral sources, as well as the ability to receive reimbursement for the full range of care they provide to both the caregiver and care recipient.

Kelly, K., Wolfe, N., Gibson, M.J., & Feinberg, L. (2013). Listening to family caregivers: The need to include family caregiver assessment in Medicaid home- and community-based service waiver programs. *AARP Public Policy Institute.*

Recommendations from this report that are particularly relevant for this current study include the following:

- Family caregiver assessments should be a part of all assessment tools for Medicaid HCBS waiver programs so that person- and family-centered plans can be established.
- Family caregivers need to be asked direct questions about their well-being, stress levels, needs for skills training, and needs for additional services.
- Care recipients' care plans must include the needs of the family caregiver identified in the assessment process.
- The assessments should be made part of the HCBS client records and electronic health records. (pp. 2-3)

Lévesque, L., Ducharme, F., Caron, C., Hanson, E., Magnusson, L., Nolan, J., & Nolan, M. (2010). A partnership approach to service needs assessment with family caregivers of an aging relative living at home: A qualitative analysis of the experiences of caregivers and practitioners. *International Journal of Nursing Studies*, *47*(7), 876–887. http://doi.org/10.1016/j.ijnurstu.2009.12.006.

According to the authors, caregivers have not historically been viewed as partners, and support services have been offered prescriptively based on the needs of the care recipient. With adequate time to build trust, nurses and other health care practitioners have the unique potential for creating an interactive partnership, based on an understanding of the complexities of caregiving and of the unique situation of each caregiver. Considering caregivers as co-experts may increase the likelihood of creating a portfolio of services that is responsive, customized, and beneficial for the caregiver. The research was completed in Canada (Quebec).

Lilly, M. B., Robinson, C. A., Holtzman, S., & Bottorff, J. L. (2012). Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. *Health & Social Care in the Community*, *20*(1), 103–112.

The aging-in-place movement has increased burdens for caregivers, with expectations to keep care recipients in the home as long as possible. At the same time, caregivers are expected to care for themselves to avoid burnout, even as respite programs are inflexible and not tailored to meet the actual needs of caregivers. The authors suggest that policies be altered to create a person-centered approach that will proactively support caregivers in seeking services, before a crisis situation arises. This study was conducted in Canada.

Lopez Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care, 12*(5). http://doi.org/10.5334/ijic.845.

The authors identified three main types of services that support caregivers: respite, psychosocial, and information/communication technology. They concluded that no single intervention can meet all the needs of a caregiver, especially given that needs are unique to each caregiver and may change over time. The authors recommend a "holistic, patient-centered approach [of] support services [that] integrate all relevant physical, psychological, and social needs of the patient" (p. 13) and the caregiver. They further state that such an approach must be collaborative and include professionals from a variety of settings. The study was completed in the Netherlands.

Martindale-Adams, J., Nichols, L.O., Zuber, J., Burns, R., & Graney, M.J. (2015). Dementia caregivers' use of services for themselves. *The Gerontologist, 00*(00), 1-9.

The authors highlight the need for providing thorough assessments that include the needs of caregivers, and consider the interdependence of care recipient and caregiver health and well-being. They suggest that assessments could be completed by the care recipients' primary care providers. Shifts in both policy and clinical perspectives would result in a focus on the dyad, including reimbursement plans that include both care recipient and caregiver, tools available for primary care providers, and comprehensive follow-up care.

Mast, M. E. (2013). To use or not to use. A literature review of factors that influence family caregivers' use of support services. *Journal of Gerontological Nursing, 39*(1), 20–28.

This article addresses the paradox between the unmet needs of caregivers and their low levels of use of caregiver respite. A review of literature by the author points to key findings that address four types of factors that exist as barriers to caregivers receiving critical supports: enabling, predisposing, experiential, and relational. A detailed table presents practical questions and strategies for managing situations determined by the four factors (p. 24).

Nursing assessment and intervention strategies based on evidence based factors

Factor	Assessment	Intervention
Service factors	■ Explore accessibility and availability of high-quality services ■ Evaluate caregiver level of knowledge and experience related to services	■ Provide accurate and complete information about services ■ Base client education, care provision, and referral for services on shared knowledge of the needs and preferences of both caregiver and care recipient ■ Mutually determine with the family services that are affordable, acceptable, and logistically feasible ■ Build trust in the professional relationship ■ Provide coordination and continuity of care across levels of health care and over time
Personal factors	■ Explore unmet needs perceived by the caregiver(s) and the care recipient and whether these perceptions are congruent ■ Identify expectations, attitudes, beliefs, and values held by the primary caregiver about his or her role and how these are influenced by factors such as gender ■ Determine the caregiver’s levels of physical and emotional health and energy ■ Assess the caregiver’s level of awareness of self-care worthiness	■ Assist the family caregiver(s) and care recipient to discuss, acknowledge, and reach agreement regarding unmet needs for support and services ■ Clarify misperceptions ■ Emphasize importance of both the caregiving role and caregiver self-care activities, legitimizing self-care worthiness
Experiential factors	■ Identify the burdens of the caregiving situation, including cognitive and behavioral challenges ■ Examine the caregiver’s and family’s past experiences with supports and services, help-seeking behaviors, and sources of resistance to accepting services ■ Evaluate the effectiveness of strategies the caregiver and other family members use to cope with the demands of caregiving ■ Assess the caregiving family’s ability to use practical, problem-focused coping abilities	■ Explore with the caregiving family which supports and services best address the burdens and unmet needs and the family’s preferences ■ Help the caregiver and family identify effective and ineffective coping strategies ■ Encourage and support the family in strengthening and/or developing practical, problem-focused coping patterns based on their constructive assessment of the situation
Relational factors	■ Identify family norms, cultural values, and sources of family conflict that influence care ■ Identify both barriers to and sources of external support from extended family and community ■ Assess congruence of caregiver’s and care recipient’s perceptions of caregiving and service preferences ■ Evaluate caregiver’s ability to differentiate inter-relational and pragmatic caregiving	■ Raise awareness of relational barriers within the family and the community that lead to isolation and deter successful caregiving ■ Help family determine strategies to build family strengths and leverage caregiving supports and resources within the community ■ Emphasize the importance of assuring adequate support early in the caregiving trajectory

The author suggests that nurses may have a unique role in supporting caregivers, given their professional responsibilities and proximity to families. As the first point of contact with families, nurses may be able to build trust and explore the complexities experienced by families, while assisting caregivers as they navigate complicated systems of health and HCBS.

Masters, J.L. (2006). The benefits of consumer-directed services for caregivers of persons with Alzheimer's disease. *Families in Society: The Journal of Contemporary Social Services*. http://doi.org/10.1606/1044-3894.3574.

A demonstration project in Nebraska, funded by the Administration on Aging, explored providing supports for caregivers through the use of flexible funding to allow them to purchase services they believed would help them most in their unique caregiver trajectories. The author stated, "For policy makers at the state and federal level [the findings] suggest that even a modest amount of money can make a difference between nursing home placement and having a family member maintain a loved one at home at a significantly reduced cost…It is the ability to choose what services will best meet the needs of those directly affected that seems to make a difference in deciding to extend the length of the caregiving role (p. 588)."

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *The Gerontologist*. http://doi.org/10.1093/geront/gnw078.

According to the authors, caregivers need assistance in two areas: managing the care recipients' care and meeting their personal needs. Caregivers' needs are multi-dimensional and require comprehensive interventions and supports. In addition, because caregivers' problems are not necessarily the same as their needs, caregivers need dynamic and customized interventions that will consider their unique situations over time. The authors concluded with a call for additional research, as well as interventions that address each caregiver's unique needs. The research was completed in Australia.

Mintz, Suzanne. (2013) The case for identifying family caregivers on medical records. Blog retrieved from http://www.emmisolutions.com/blog/2013/10/23/the-case-for-identifying-family-caregivers-on-medical-records.

In 2013, the Commission on Long Term Care recommended that family caregivers receive documentation on medical records. Suzanne Mintz, the co-founder of the National Family Caregivers Association, also urges health care systems to acknowledge and involve family caregivers as primary care providers and critical members of the health care team. Including information about family caregivers on medical records could allow health care systems and staff to provide more efficient and cost-effective care.

Mittelman, M. & Bartels, S. (2014). Translating research into practice: Case study of a community-based dementia caregiver intervention. *Health Affairs, 33*(4), 587-595.

The authors tested an evidence-based intervention with caregivers in the community in mostly rural locations in Minnesota. Based on the results, they recommend adapting the intervention protocols in the following two ways:

- Reduce the time burden of the assessment
- Implement a telehealth component in order to link providers and caregivers who are unable to participate in in-person sessions

Montoro-Rodriguez, J., Kosloski,K., & Montgomery, R.J.V. (2003). Evaluating a practice-oriented model to increase the use of respite services among minorities and rural caregivers. *The Gerontologist, 43*(6), 916-924.

The authors believe that a practice-oriented model that addresses knowledge, access, and intent may provide a useful tool for encouraging the use of respite services by caregivers. Altering the way services are offered and addressing the beliefs of caregivers are two fundamental ways of implementing such a model. The authors determined that manipulating the elements associated with each factor of the model can influence use of services for White and Hispanic caregivers, but less so for African American caregivers. The factors and elements are summarized in the table below.

Factor	Elements
Knowledge — Information needed to use a service	■ Perceive benefit ■ Aware of the service ■ Knowledge of steps required to access service
Access — Freedom from barriers	■ Transportation ■ Affordability ■ Availability at time and in amounts needed

Factor	Elements
Intent — Caregivers' intent to use the service	■ Attractiveness/desirability ■ Preference for cultural similarity ■ Attitudes toward receiving help

National Academy of Sciences. (2016). Families caring for an aging America. Retrieved from http://www.nationalacademies.org/hmd/Reports/2016/families-caring-for-an-aging-america.aspx.

A convening of nationally recognized experts assessed the current state of family caregiving, as well as its impact on individuals' well-being. The experts also developed and recommended policies to better address caregivers' needs.

Key observations outlined by the convening include the following:

- The gap between supply and demand of informal caregivers is growing
- Families are increasingly diverse
- The caregiving experience is unique and varied
- The impact of caregiving on the caregiver is unique and varied
- Caregivers are key players in care, but continue to be marginalized
- Interventions that successfully support caregivers are available, but not to all informal caregivers

The most urgent recommendation offered by the convening calls for a shift from person-centered care to person- and family-centered care. The convening also urges U.S. government agencies to develop and implement a national strategy, which includes the following components:

- "Effective mechanisms to ensure that family caregivers are routinely identified in delivery of services to older adults with impairments
- Medicare and Medicaid payment reform to motivate providers to engage family caregivers effectively
- Training of health care and LTSS providers to engage caregivers
- Dissemination and funding for evidence –based caregiver services
- Evaluation and adoption of federal policies that provide economic support to working caregivers

- Expansion of the national data collection infrastructure to create a knowledge base about caregivers" (p. 3, Report In Brief)

National Caregiver Alliance. (2016). Atlas of caregiving pilot study. Retrieved from http://atlasofcaregiving.com.

With a grant from the Robert Wood Johnson Foundation, the National Caregiver Alliance completed a study to gain a better understanding of the lived experiences of caregivers. Key findings include:

- Caregivers are not fully aware of the extent of their caregiving activities
- There is typically more than just one caregiver
- Finding respite is difficult and requires contextual knowledge and detailed preparations
- The work of caregiving involves constant change
- Caregiving responsibilities and burden are not defined only by the disease or condition
- Caregivers are often too overwhelmed and the situation is too changeable to allow for proactive responses
- Online caregiver forums can be a convenient method for support
- The stress and exhaustion of caregiving are cumulative

Researchers recommended the following:

- Caregivers may be willing to use a new product or method, but need reassurance that it won't further complicate their lives
- Judging the usefulness of an intervention is more accurate than assessing usage
- Make interventions easy to use so that the cognitive burden is minimized
- Caregivers will only use services and supports if they fit into the daily routine of caregiving
- Providers must consider the social context for each unique caregiving network

Phillipson, L., Magee, C., & Jones, S. C. (2013). Why carers of people with dementia do not utilize out-of-home respite services. *Health & Social Care in the Community, 21*(4), 411–422. http://doi.org/10.1111/hsc.12030.

Many promotional messages about respite care focus on the benefits to caregivers. However, caregivers who do not use respite care reported that they believe such care situations may not benefit or may even result in negative behavioral or functional outcomes for the care recipient. The authors suggest that addressing service quality and promoting the positive impacts of respite care for both the caregiver and the care recipient may reduce resistance to respite care use. Even so, the authors acknowledge that respite care may not meet the preferences of all persons with dementia or their caregivers, and suggest that further research be conducted to determine additional ways of meeting these preferences. The research was completed in Australia.

Phillipson, L., Jones, S. C., & Magee, C. (2014). A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. *Health & Social Care in the Community*, *22*(1), 1–12. http://doi.org/10.1111/hsc.12036.

The authors reviewed Andersen's 'Behavioral Model of Service Use' in light of predisposing characteristics, enabling factors, and need factors for caregivers to persons with dementia. They determined that barriers to service use by caregivers to persons with dementia are varied and personal. A coordinated approach may serve to minimize barriers for caregivers, by considering the personal needs and situations of individual caregivers, as well as broader strategies to address system-wide barriers of financial hardship, stigma, and complex pathways to services. In particular, assistance in navigating the service system by connecting caregivers directly to supports may prove to be more helpful than simply providing information about the availability of services. The research was completed in Australia.

Qualls, S.H. (2016). Caregiving families within the long-term services and support system for older adults. *American Psychologist, 71*(4), 283-293.

The author begins with the assertion that psychologists have a unique role in integrating the "assessment of family members' well-being and the contexts of caregiving…into various settings in which families interface with service delivery systems" (p.283). Given the complexities of family relationships and health care delivery systems, changing disease trajectories, and the high stakes of care transitions, it is particularly critical to involve family caregivers as key players in care coordination. The author notes that promising approaches include integrating caregiver assessments and supports into primary care and other service systems, as well as considering the home environment and social contexts of the caregiving relationship. Medicare regulations may need to be adjusted in order to provide reimbursements to family members who manage necessary medical tasks.

Reinhard, S.C. & Choula, R. (2012). Meeting the needs of diverse family caregivers. *AARP Public Policy Institute.* Issue 69.

This article highlights the importance of elevating the visibility of family caregivers and recognizing them as both providers and clients. Non-White caregivers want to provide the care for their family members, and expressed a need for additional accommodations and supports with access to information, training, and a 24-hour hotline.

Robinson, K. M., Buckwalter, K., & Reed, D. (2013). Differences between dementia caregivers who are users and nonusers of community services. *Public Health Nursing, 30*(6), 501–510. http://doi.org/10.1111/phn.12041.

The authors considered the important role of public health nurses in connecting caregivers to useful and relevant community services that focus on problem-solving, caregiving skills, and support. The study was completed in 2013 on data from 1995-1997. Replicating the study with more recent data may be useful in considering stable or emerging trends.

Samia, L., Hepburn, K., & Nichols, L. (2012) "Flying by the seat of our pants": What dementia family caregivers want in an advanced caregiver training program. *Research in Nursing & Health, 35,* 598-609.

This article highlights the unstable nature of the conditions that define the caregiving relationship. The authors note the importance of multiple interventions with caregivers, and the value of program supports that are flexible and responsive.

Scharlach, A., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work, 47,* 133-156.

The authors report that non-White and Hispanic caregivers under-utilize supports and are hampered by barriers related to familism (e.g., cultural norms related to family responsibility), group identity (e.g., "us vs. them" perspective), and service barriers (e.g., reliance on informal support, mistrust of service providers). In particular, many current programs and services are targeted to individual caregivers, rather than the family system. The authors suggest that expanding community partnerships between aging network programs and ethnically or culturally specific providers could allow for improved recruitment and participation, as well as improved capacity in these communities (p. 152).

Stern Center for Evidence-Based Policy. (2016). Addressing the needs of caregivers at risk: A new policy strategy. University of Pittsburgh.

This policy paper is a call for an overhaul of the current caregiver programs, which the authors describe as a "patchwork of small, uncoordinated programs that do not yet meet the current and future needs of [family caregivers] (p. 4)" In addition to changes that would reduce financial hardships and improve flexibility in employment, the paper reports that services and supports are also limited and inconsistently available from state to state. Analysis has determined that family caregivers would benefit from expanded access to caregiver information and non-traditional services (e.g., assistive devices, house modifications, personal care assistance), along with more support to choose the care they do arrange for their family members.

Stirling, C., Andrews, S., Croft, T., Vickers, J., Turner, P., & Robinson, A. (2010) Measuring dementia carers' unmet need for services—and exploratory mixed method study. *BMC Health Services Research, 10* (122), 1-10.

Standard measures that assess caregivers' burden levels (normative needs) are inadequate for helping caregivers of persons with dementia access support services. The authors determined that the complexities of caregivers' characteristics and situations benefit from a more person-centered approach. Specifically, responding with flexible options to the needs that were expressed by caregivers themselves may improve the likelihood that caregivers will accept help.

Stockwell-Smith, G., Kellett, U., & Moyle, W. (2010). Why carers of frail older people are not using available respite services: an Australian study. *Journal of Clinical Nursing, 19*(13/14), 2057–2064.

According to the authors, many caregivers feel disempowered by a fragmented and prescriptive system of services. Past negative experiences with high staff turnover and a lack of consistency, a high degree of investment in their roles as caregivers, feelings of responsibility for the care recipient, the volume of informational materials provided, and assessments that exclude (rather than empower) do not facilitate the process of seeking support. The authors call for "mechanisms to inform and communicate with carers and guide service delivery changes towards a model of care which engages and promotes user control and foster genuine participatory relations" (p. 2063) for caregivers. The study was completed in Australia.

Warrick, N., Peckham, A., Watkins, J., Padjen, M., and Williams, A.P. (2014) Caring for caregivers of High-Needs Older Persons. *Healthcare Quarterly, 17*(3), 24-29.

The Caregiver Framework for Seniors Project (CFSP) is an initiative that seeks to improve caregivers' resilience and ability to continue in their caregiving roles. Key findings from a study of the methods and outcomes revealed three main points:

- Caregivers and care recipients should be considered a unit and receive access to services in a way that acknowledges the role of the caregiver
- Caregivers should engage in self-management of services and supports with the support of care coordinators. Flexible funding further boosts the ability of caregivers to meet their needs.
- CFSP works best when initiated before a crisis situation.

This study was completed in Canada (Toronto).

Wennberg, A., Dye, C., Streetman-Loy, B., & Hiep Pham. (2015). Alzheimer's Patient Familial Caregivers: A Review of Burden and Interventions. *Health & Social Work, 40*(4), e162–e169. The authors describe a model for caregiver interventions that includes:

- Comprehensive approach to addressing the needs of the caregiver and care recipient
- Individually tailored and person-centered focus
- A menu of options that reflects desires and needs of the caregiver and care recipient
- An interdisciplinary team with physicians, nurses, social workers, and health coaches
- Culturally and ethnically relevant practices
- Evidence-based activities that promote cognitive health and social interaction (e.g., aerobic exercise and cognitive tasks)
- Holistic approach to health and quality of life

Appendix E: Findings from current MN studies and reports

2015 survey of older Minnesotans: caregiving issue brief

In 2015, the Minnesota Board on Aging and Minnesota Department of Human Services partnered to complete the Survey of Older Minnesotans. The information in the survey is used to capture a snapshot understanding of the "status and needs of older adults (p.3 Background)."

Highlights of key findings include the following:

- The rate of caregiving and the proportion of older adults with an unpaid caregiver decreased until 2001 and is now increasing.
- Over half of older adult caregivers report providing care for someone with memory loss.
- Nearly a third of older adult caregivers are considered "higher-hour" caregivers, those providing at least 21 hours of care per week.
- Approximately 30 percent of older adult caregivers perform medical or nursing tasks.

MBA and MN DHS recommended the following strategies to support family caregivers:

- Expanding policy and services to support family caregivers. Examples include expansion of sick leave benefits, the proposed CARE (Caregiver Advise, Record and Enable) Act to notify caregivers about transitions of care and provide live instruction about medical tasks the caregiver will perform at home, and proposed RAISE (Recognize, Assist, Include, Support and Engage) Family Caregivers Act to develop an integrated national family caregiving strategy to recognize and bolster support for caregivers.
- Expanding family- and person-centered care in all settings, and services such as information, education, caregiver coaching, and respite options to respond to diverse and changing needs.
- Targeting services and support to ”at risk” caregivers early on including those who are stressed or depressed, those caring for someone with Alzheimer’s or a related dementia, higher-hour caregivers and those performing medical or nursing tasks. This also includes those who report fair or poor health status as a result of caregiving, those with limited financial resources, racial and ethnic minorities and rural isolated caregivers.

- Increasing efforts to support older adults who do not have a family caregiver to help them if they are sick or disabled, especially for those who are age 85 and older, not married, live alone, and have lower incomes. This includes addressing gaps in services such as IADLs, and others identified in the Gaps Analysis[27] and Critical Access studies[28] and using technology to enhance support.

- Promoting the use of technology where appropriate to enhance in-person services and support, to monitor health and vital signs, decrease reliance on paid caregivers, and reduce workloads. Examples include telehealth technology, personal emergency response systems, home monitoring systems, home modifications, adaptive equipment, electronic organizers, and others.

- Promoting workplace policies and support for family caregivers to assist them in juggling the competing demands of work, caregiving and family. Examples include expanding of workplace flexibility (e.g., flexible hours, telecommuting and reduced work hours), paid sick leave for private and low income workers who lack access to paid sick days, and extending Family Medical Leave Act protections for employees working at small businesses. Supporting employee caregivers enhances productivity, lowers absenteeism, improves retention, results in fewer workplace disruptions, and promotes a competitive edge in recruiting high quality employees.

AARP caregiving policy workshop summary report

AARP of Minnesota, the Alzheimer's Association of Minnesota-North Dakota, and Wilder Research partnered to conduct three workshops on public policy priorities for caregiving in 2013. The purpose of the workshops was to provide a forum for hearing the opinions of current and former caregivers, as well as individuals on the front-line of policy work in caregiving.

Top policy priorities identified by the participants include:

- Education and information: providing education about caregiving, having one point of contact for information, having access to information before a crisis

- Coordination between systems: improving communication and integration between agencies and institutions to provide better supports for caregivers (e.g., access to EMRs across systems, reducing administrative obstacles)

- Access to services and supports: access to more respite care is critical, and health care systems must focus on caregivers

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[27] Source. DHS Gaps Analysis Study https://mn.gov/dhs/partners-and-providers/continuing-care/data-measures/gaps-analysis/current-study/

[28] Source. http://www.dhs.state.mn.us/main/groups/aging/documents/pub/dhs16_197982.pdf

Key suggestions include:

- Improving support by implementing a peer support system with past caregivers
- Continuing to educate and reach potential caregivers

Caregiver public awareness campaign

Wilder launched an awareness campaign to help caregivers understand that resources are available to support them. Since 2011, the awareness campaign has resulted in more than 100 million media impressions statewide, and has also translated the campaign messages into Spanish, Hmong, Khmer and Somali. More than 700 campaign toolkits have been distributed across the nation to spread the message that support is out there for people caring for a friend, neighbor or relative.

Caregivers to older adults

Note. Information from this study is also reviewed in the Findings section of the report.

In 2013, Wilder completed a study with caregivers in the Twin Cities metropolitan area. More than 100 caregivers participated in 13 focus group discussions about their experiences. The Caregivers to Older Adults study was designed to answer the following main questions:

- Why do caregivers not take advantage of existing caregiver support services
- To what extent does the current array of caregiver support services represent a “good fit” with the actual needs and conditions of caregivers?

Barriers mentioned by caregivers that prevent them from taking advantage of existing supports include:

- Lack of awareness of services
- Need for supports that meet cultural needs and expectations
- Concerns about the quality of services
- Care receivers’ resistance to using services
- Cost of services
- Reliance on informal support from family, friends, and non-relatives
- Failure to recognize the need for help
- Difficulty finding sources of useful information

Caregivers reported making connections to services through a random process of gathering information, or based on specific needs at the time. They also accessed services in a crisis situation, or when outside help was required to meet the care recipients' needs.

Caregivers believed they would benefit from the following supports:

- Easy access to information
- Opportunities to connect with others for support and education
- In-home and community-based services that are flexible, trustworthy, reliable, consistent, and affordable
- Additional formal and informal services that offer daytime and overnight respite, transportation assistance
- Workplace supports
- Availability of culturally relevant services in those communities

Recommendations based on the findings included:

- Begin with the assumption that every first door should be the right door for a caregiver to begin accessing support.
- Create opportunities for contact with experienced caregivers.
- Take advantage of the fact that caregivers put their care recipient first.
- Provide caregiver education to middle-aged (and older) adults in multiple settings.
- Make workplace education and attention to the needs of caregivers the norm and not the exception.
- Make early identification of needs and opportunities for joint caregiver/care recipient participation a focus of services to caregivers serving those with memory loss.
- Consider the application of evidence-based programs that use behavioral activation as a strategy for reducing depression and stress among caregivers.

Caregiving in context

In fall 2011, Wilder Research conducted telephone interviews with 212 informal caregivers of older adults living in seven St. Paul neighborhoods. The study was one part of a community initiative designed to strengthen the fabric of support for family, friends, and community caregivers. The purpose of the study was to better understand the informal networks of support that allow caregivers to sustain their efforts, as well as challenges and needs for supports.

Caregivers reported needing additional help with:

- Accessing information about services and financial assistance
- Coaching and problem-solving related to caregiving challenges
- Understanding which services are of the highest quality
- Finding other caregivers to talk with and places to connect for support and education
- Respite care
- Help with basic needs like transportation, financial support, and care

Other results include the following tables, referenced in the findings section of the report.

Note. Information from this study is also reviewed in the Findings section of the report.

E1. Where caregivers say they would look for information (N=141)

	Primary caregivers
Medical sources (e.g., doctors, nurses, hospice care, etc.)	26%
Internet or websites	25%
Case manager or social worker	16%
County or state social services	14%
Community-based organizations	14%
Family members or friends	10%
Senior LinkAge® Line/AAA	6%
Staff at a nursing home or residential facility	5%
Other	18%

Note. Open-ended responses were coded for themes; responses are not mutually exclusive.

E2. Home-based services caregivers reported using in the past month (N=117)

	Primary caregivers
Any assistance from an organization or business	54%
Nursing care from a home health aide (i.e., changing dressing or giving medicine)	25%
Transportation or rides	17%
Personal care from a home health aide (e.g., bathing, dressing, grooming, eating, etc.)	16%
Home-delivered meals	15%
Housekeeping help	15%
Heavy chores (i.e., mowing grass, shoveling snow, heavy housecleaning)	7%
Shopping help (including home delivery)	5%
Adult Day program	5%
Preparing meals	4%
Correspondence or paperwork (i.e., filling out forms for insurance, Medicare, or other services)	3%
Respite care (daytime or overnight)	3%
Managing finances (e.g., keeping track of bills, writing checks, etc.)	0%
Other	2%

Note. Percentages total more than 100 due to multiple responses.

E3. Help caregivers reported receiving from others in the past month (N=117)

	Primary caregivers
Any assistance from family members, friends, or neighbors	56%
Heavy chores (i.e., mowing grass, shoveling snow, heavy housecleaning)	31%
Transportation or rides	19%
Housekeeping help	16%
Correspondence or paperwork (i.e., filling out forms for insurance, Medicare, or other services)	14%
Shopping help (including home delivery)	13%
Managing finances (keeping track of bills, writing checks, etc.)	11%
Preparing meals	9%
Nursing care from a home health aide (i.e., changing dressing or giving medicine)	4%
Daytime respite care	3%
Overnight respite care	3%
Personal care from a home health aide (e.g., bathing, dressing, grooming, eating, etc.)	2%
Home delivered meals	2%

Note. Percentages total more than 100 due to multiple responses.

E4. Most important resource caregivers reported currently having in place to support their role as caregiver (N=141)

	Primary caregivers
Support from family members, friends, and others	62%
Health care resources (e.g., health care providers, nursing or assisted living staff, and home health aides)	48%
Home-based services (e.g., Meals on Wheels, chore help, transportation assistance)	15%
Community-based resources (i.e., community service organizations, referrals for services, or advice)	8%
Faith-based resources	6%
Personal resources (i.e., hobbies, flexible job, caregiving experience, social activities)	6%
Professional services (i.e., social worker, case managers, or mental health professionals)	4%
No resources in place	5%

Note. Open-ended responses were coded for themes; responses are not mutually exclusive.

Creating a dementia capable health care home (Lakewood Health System)

Wilder conducted telephone interview with family caregivers who had been served through the dementia initiative by the Lakewood Health System. Families believed they had received significant benefits from the immediate and supportive access to health care providers through the medical home services.

Other key supports mentioned by family caregivers as particularly helpful include:

- Alzheimer's support group, which included respite care
- Powerful Tools for Caregivers classes, which included respite care
- Respite care
- On-line research

Barriers that keep people from accessing supports include:

- Transportation
- Low income and inability to pay for services
- Navigating the system to find and arrange for services and supports

Other services requested by family caregivers include:

- Financial advice
- Adult day health that is accessible in rural locations
- Companion service
- Regular communication
- Customized engagement based on the unique circumstances of the care recipients

Medtronic Foundation grant

In 2013, Wilder Foundation received a grant to implement an innovative partnership with primary health care clinics, in which caregivers would be identified, engaged and referred to Wilder's Caregiver Services program. Salient findings include the following:

- Empowering any clinic staff person to identify potential caregivers and make a referral to the health care home resulted in positive connections between caregivers and care managers.
- Caregivers' resistance to accepting help was eased by establishing trust with clinic staff and Wilder staff.
- Early intervention opportunities with caregivers can improve patients' experiences with being cared for at home.

Minnesota Family Memory Care (MN's implementation of the NYCUI 2007-2010)

This study reviewed the process and costs of the implementation of the NYCUI evidence-based program over three years in Minnesota, as well as the experiences of caregivers (Paone, 2012). Key descriptive and process findings include the following:

- Fourteen program sites implemented the Family Memory Care program, with caregiver consultants managing the program and working on-on-one with family caregivers.
- Recruiting spousal caregivers was challenging. A total of 128 family caregivers completed the initial assessment.
- The average cost per caregiver ranged from $3,488 (Year 1) to $4,791 (Year 3). Program implementation is labor-intensive.
- The program relies on one staff caregiver consultant with specialized training. Sustaining the relationships with family caregivers depends on continuity of the staff, high quality training, and personal attributes.
- Program sustainability may require changes to policy and payment rules, and will depend on consumer demand, "organizational readiness/commitment, and the impact of health insurance and health care provider reforms..." (p.14)

Minnesota Gaps analysis study

The 2013-2014 Gaps Analysis study was completed to assess the capacity and gaps of the Minnesota services system to support older adults; persons with disabilities; and children, youth or adults living with mental health conditions. The long-term services and supports system includes home and community-based services and a continuum of mental health services and supports. Sources of information include lead agencies, providers, consumers and caregivers, and key stakeholders.

Findings about services related to HCBS caregiving supports and Title III-E funding include the following:

1. Lead agency representatives rated transportation, chore services, personal care assistance, and respite care among the largest or most significant gaps between older adults' needs and the availability of services to meet them.
2. Transportation is the service most often identified by older adults as their greatest unmet need.
3. Both lead agencies and service providers identify low provider reimbursement rates as the top reason for service gaps, together with the related problems of recruiting and retaining those who provide services.
4. Low provider reimbursement rates were most often associated with gaps in chore services, non-medical transportation, and personal care assistance.
5. Shortages of in-home respite care were primarily associated with inconsistent demand and difficulty of retaining or recruiting providers.
6. Lead agencies and providers believe that key strategies for reducing barriers faced by older adults include access to better information, improved funding streams, increased transportation, and additional housing supports and options.

Source. DHS Gaps Analysis Study https://mn.gov/dhs/partners-and-providers/continuing-care/data-measures/gaps-analysis/current-study/

Return to Community Initiative

The Return to Community Initiative is an evidence-based reform initiative that seeks to facilitate transitions for older adults from nursing homes to the community. Because caregivers are an essential component of successful transitions, information was collected about the caregiving experience to better understand the initiative. Nursing facility residents who transitioned to the community had:

- Moderate functional dependency
- Mild to moderate cognitive impairment
- Good caregiver availability, including 80 percent who anticipated having support available during the day and night

Supporting the family caregivers of older adults

In 2011, the Aging and Adult Services Division of MN DHS completed a study with care managers and LTCC assessors to identify practices and perspectives for supporting family and informal caregivers under Elderly Waiver and Alternative Care programs. The results are used to identify gaps, barriers and opportunities in the current system, to address service re-design issues, address care manager needs/requests and establish baseline data for further evaluation.

Care managers reported referring caregivers most often to the following services:

- Homemaker services
- Home delivered meals
- Adult day care
- Respite care
- Caregiver support groups
- Chore services

Care managers reported the following main barriers to accessing services:

- Reluctance by caregivers to use help
- Service availability
- Caregivers are not aware of services or benefits

- Provider availability
- Not interested
- No respite available to allow caregiver to attend something

Care managers also mentioned the following gaps in services to support culturally diverse caregivers:

- Enough culturally-specific programs and services
- Interpreters or bilingual workers
- Respite care
- Caregiver training/education
- Support groups

Additional related thoughts shared by care managers include the need to:

- Provide resources and training to improve the ability to assess, identify, and support "at risk" caregivers
- Meet the ongoing need for culturally-specific programs and culturally-competent staff
- Address gaps in capacity of services in rural areas

Appendix F: AAA questions

1. How would you describe the strengths of the caregiver services currently funded by your agency under Title III-E?
2. What are you looking for when you review proposals from potential service vendors who are interested in providing caregiver services?
3. Since Title III-E funding first became available to fund and support caregiver services, what adjustments have you made in your funding strategies?
4. In your estimation, which service providers funded by your agency are doing the best work in supporting caregivers within their respective communities? Why do you consider their work outstanding?
5. What do you consider the key challenges in making caregiver services and supports accessible to those people who can most benefit from them?
6. What adjustments have service providers made in their engagement and service delivery strategies?
7. Do you feel that you now get enough information from caregivers being served in your region to gauge the value and quality of the caregiver services you are funding?
8. What one or two things do you feel would be the most valuable outcomes from this study?
9. How would you hope to be able to use the information generated by this study? What would make it especially useful to your agency? What types of decisions might it inform?

Appendix G: Additional comments from key informant respondents

Self-directed grants

One AAA respondent summarized the potential of self-directed grants in this way:

> *That is something our Return to Community staff talk about…Finding people at these junctures where there are transitions and working with the health care systems to develop transitional care plans and incorporate caregiver support is where we are going to have our best impacts in serving the family caregivers.*

Caregivers' awareness of and access to services

Examples of comments about caregivers' awareness of and access to services include the following:

> *In the rural areas, there are still many people who are unaware of services. People feel it's their duty [to be caregivers].*
>
> *It mostly just doesn't occur to caregivers that there is service available to them at all, that there might be something that would helpful to them in their caregiving role. And since that isn't in their knowledge, knowing any particulars about services is another further step removed.*
>
> *Caregivers don't know until they get involved in a group or class. Then many say, "I wish I had known all this five years ago."*

Comments that illustrate the ways in which awareness and ability to seek supports allows caregivers to navigate the system include:

> *Caregivers who are already in the service stream know better how to access services.*
>
> *Our older seniors are not as knowledgeable as our younger seniors who know how to access information using technology.*
>
> *Do caregivers actually see it as something potentially valuable? Or do they feel like it's just another stressor that they can't deal with right now?*
>
> *This is the million dollar question. How to coordinate what is available and how to use what is available, and what's culturally relevant.*
>
> *There is a lack of knowledge about how to access support, as well as concern about the process and what the services are going to cost.*
>
> *If they are out on their own, it's a little overwhelming to know where to start.*

Ideas for improving awareness and access to services

Comments that illustrate ideas for finding caregivers and building awareness and access include the following examples:

> *We need to continue to work with health care providers (who interact with caregivers every day) to embed resources or information in their practice, making a seamless access so that caregivers don't have to learn about resources on their own.*
>
> *Caregivers get so isolated. They are not getting out as much, people are not visiting them as much, and it can even be hard for them to go to church. So we try to think about where they do go, and were we can get the information to them.*
>
> *The biggest thing is to get them to recognize themselves as caregivers. It's the one-on-one contacts with people that help with this.*
>
> *Have a little video, like a two minute YouTube video, with someone giving testimony in very practical terms about what a caregiver consultant did for them.*

Comments that illustrate respondents' cautions to understand the needs and unique journeys of caregivers, as well as the need for trust include the following:

> *We need to think carefully about the needs of caregivers. The methods of reaching caregivers that we have thought are tried and true, may not really be what a caregiver wants.*
>
> *We need marketing and outreach aimed at immigrant and minority groups.*
>
> *Think about where they are in their caregiving. It's tricky because some enter at a point of crisis, while others may have been providing assistance for long periods of time. Individuals will all need different kinds of outreach and support.*
>
> *It's personal. It's about relationships. Caregivers need a face and a name, and somebody they have talked to before.*

Addressing resistance to accepting help

Comments related to the importance of building relationships to address resistance to accepting help include the following examples:

> *A lot of it is about building a relationship with the family member. Provide them with information and education at the outset, but don't stop there. Don't just simply take a passive approach and hope the caregiver engages with you. It requires ongoing follow-up with families every few months to see how things are going and if things have changed. Over time, those individuals might become more amenable to services.*
>
> *There has to be trust and respect for who is providing the services.*
>
> *It's about the relationship piece and people getting to know who you are. Recognize that sometimes it takes multiple calls to get the conversation started, and the ongoing follow-up is important.*
>
> *If you are able to establish a relationship, and keep in touch on an ongoing basis…you can maybe ease into it and reassure them…or tell them stories about how it's working for other people.*

Comments related to reframing the language surrounding the offer of help include the following examples:

> *Sometimes it's just framing it in a way so that caregivers feel ok and comfortable using the program. Baby boomers tend to be more okay with accepting services than those in the older generations.*
>
> *I don't sell it like it's "help." It's more like we are sharing this journey with you. I'm here to partner with you and we are in this together. The "help" word deters people.*
>
> *Focus on the care receiver and how the care receivers will benefit rather than how the caregivers will benefit themselves. They want to see how their loved ones will benefit.*
>
> *We need to empower caregivers to access resources, as opposed to framing it in a negative way and telling them, "You have burden and stress. Go to a support group." Talk instead about the normal trajectory of caregiving as building a network of support around yourself.*
>
> *We tell caregivers that we are not here to overtake what they are doing, but rather to lighten their load just a little.*

Comments related to discerning what caregivers want include the following examples:

> *Sometimes the resistance is because they don't know the workers who come in or the hours are not good for them. Make it more person-centered and convenient. Make it more self-directed.*
>
> *It may be rethinking what some services mean. Respite may not be what the family member wants. It may be having family meetings and talking about the situation and….about what may bring relief to the primary caregiver. Rethink what respite means.*
>
> *It doesn't matter where they are in the journey. Some need more and some need less support. It's wonderful to be able to honor people, to serve, to be very person-centered, and work with them where they are.*
>
> *Sometimes caregivers do need formal services, but sometimes they can find the support they need in their own informal networks.*

Types of help that make the most difference for caregivers

Examples of comments that reflect respondents' perspective that one size does not fit all for supporting caregivers include the following:

> *It is important to have a good assessment approach that isn't too burdensome, that also allows you to pinpoint what the family caregiver prefers, what they would potentially need, and then try to match them most effectively that way. A person-centered approach.*
>
> *The most beneficial help for caregivers involves a blend of emotional support, self-care suggestions, education, and a break from caregiving. We need to be able to adapt our approach to fit the individual needs of the caregivers.*
>
> *It's the more comprehensive programs that are tailored to the specific needs and circumstances that have the most impact. The most effective programs are nuanced, involve an assessment, and are tailored to reflect the underlying challenges.*

Examples of respondents’ comments about the importance of personal connections include the following:

> *The psychological connection with other caregivers has proven to be really huge. It’s who can serve you without making you feel like you are not doing a good job, or belittling you.*
>
> *Support groups where caregivers can get the resources they need and interaction with people who understand what they are experiencing.*
>
> *Someone to talk to who just listens non-judgmentally, and helps you work through challenging times. Feeling like you have practical support and are not alone in your journey.*

Examples of effective programs or service models

Examples of respondents’ comments about qualities that make programs effective include the following:

> *We focus on aging life care management (rather than caregiving coaching) to work directly with the provider, help with the scheduling, coordinate the information, and make sure everyone who needs it is getting help. It has a lot of flexibility, depending on the individuals’ needs.*
>
> *[I use] the caregiver burden assessment… questions to have a discussion to see what the caregiver is feeling and give them an opportunity to talk about it in a way they know won’t go back to the rest of their family.*
>
> *It’s about honoring and recognizing different family systems, listening, understanding the cultural context, and establishing trust.*
>
> *I think what really helps is that they have someone to talk to and know where to go for information.*
>
> *The next step is to find mechanisms that match family caregivers with the services they are most likely to benefit from.*

Respondents offered the following perspectives about caregivers’ access to self-directed services:

> *Self-directed care is only effective if the family caregivers know where to get services that can help them.*
>
> *Certain kinds of people could do it and it was a huge help in some instances. But there were as many cases where they just couldn’t deal with all the paperwork.*
>
> *If the paperwork process could be simplified to reduce barriers to access, I like the idea that it would empower the caregiver to seek out services that would provide support to them, rather than just being given a prescriptive list of services.*
>
> *With caregivers, the benefit only comes if it is easy. They don’t need more work.*
>
> *When people opt into this service [self-directed care] they do like it, because it gives them a lot of flexibility, and they are able to use trusted workers.*

Addressing caregivers' barriers for getting services

Examples of respondents' comments about barriers for caregivers include the following:

> *People don't think they need [help] because they may think it's a sign of weakness or lack of capacity on their part. It's just one more thing in their busy schedule.*
>
> *A lack of a societal or community understanding and recognition of the role of the caregiver and the needs that they have.*
>
> *When people get to the point where they acknowledge that they need help, they often don't know how they are going to pay for it.*
>
> *People don't recognize themselves as caregivers, and so they don't think they need services.*
>
> *It's not just a lack of awareness on the part of the family caregivers themselves, it's a lack of awareness in context—the community context, the employment context, the health care provider context that these family caregivers are living in and are engaging in on a daily basis.*
>
> *A lack of awareness of the services that exist, and a lack of understanding about how to find them.*

Examples of respondent's opinions about reducing the barriers include the following:

> *[Caregivers] need to be a routine part of [medical] practice. For annual wellness visits under Medicare, providers are required to screen for cognitive impairment and depression. But providers cannot bill to spend time with family members. That what we have to change.*
>
> *The movement toward things like age-friendly communities and what we've seen in ACT on Alzheimer's…is very strong stuff in the right direction, because it starts to improve and enhance awareness of family caregiving as an issue and of the services that are out there.*
>
> *I can't emphasize too much an awareness campaign and marketing. People will come when they are ready. But when they are ready, do they know where to come?*
>
> *It's normalizing that the caregiver is as much of a part of the care team as the doctor, nurse, and care receiver are.*
>
> *In general, if AAAs had a really strong national push about family caregiving in general… Almost like the* Got Milk? *campaign or something like that.*
>
> *Trying to infuse more flexibility into how we use Title III resources, and going at it from the angle of helping the caregiver get done what they need to get done, first and foremost.*
>
> *All kinds of technology and on-line access to resources. These can be especially helpful to working caregivers.*
>
> *More work with different types of media…A lot of our elders are not tech savvy, and some of them can't afford internet [service].*

Additional observations and issues to consider

The following comments are representative of the variations in support ideas among the various expert study participants:

> *So much of this is about capacity and funding. If we got more funding for caregiver support services, we could really boost what we are doing.*
>
> *I just wish there was a pot of gold at the end of the rainbow to pay for services to get the word out there. And more money for respite services.*
>
> *There are really complex, urgent issues that caregivers are bringing, besides just the "I'm stressed and I could really use a respite break." Those are the things that require our professional attention first and foremost – and they are happening more and more often. Things like multiple care receivers for one caregiver, multiple caregivers with different needs, complex family relationships, mental health concerns, and imminently and truly homeless older adults and caregivers.*
>
> *There needs to be a stronger strategy in terms of modifying those caregiver services that can be more responsive to where the health care system is going. And so truly making it person-centered. Wherever the person is touching the system, there have to be different kinds of caregiver support there. But you have got to bring in more health care people – like community paramedics, nurses, who can provide that rapid, intense caregiver education and support.*
>
> *Caregivers can't get out because of respite issues, or because they are isolated. So we have evolved, and now we bring it to them in the home – whether it's by the telephone, or by computer, or Skype, or Facebook, or iPhone, or whatever they are used to.*
>
> *The medical system being more proactive in checking in with caregivers, and asking, at different points, what help they are getting, what else would be useful. People are very tuned in to what their physicians say, especially when there is a serious diagnosis, and something involving heavy care.*
>
> *We are losing nonprofit agencies and organizations that want to use volunteers to provide caregiver services, because state grants are getting more difficult to put together; waivered dollars to help with companion programs and caregiver issues require too much paperwork and requirements are too difficult. More funding would help small nonprofits have the ability to put more of their time into programs and spend less time on administration and fund raising.*
>
> *It's imperative that we educate our communities about the need for having important documents like power of attorney and health care directives in place, as well as services that could help caregivers reduce stress, and potentially avoid crisis situations and things like unnecessary visits to the hospital or ER.*
>
> *You have two senators who understand this issue and are popular in your state. What about if you were able to get them to do some messaging – TV, radio?*
>
> *There is a need for a national council on caregiving. We need a national caregiving initiative that includes the federal government, state agencies, the private sector, volunteers, and private philanthropy. We need to provide a blue-print for building an evidence-based system of support.*
>
> *Education events are becoming more important than the small caregiver support groups. Fewer younger people come to support groups. Education events are still well attended.*

> *Serving diverse communities is important. Do we understand what we need to do to support these caregivers? We need to push the limits to define "support" so that it can be provided. Where do we need to adjust our services so we are more available and flexible? Where can we connect with caregivers where they have needs and move them into places where they can get help?*
>
> *Not all older people need help – many are able to function fine on their own, and not all families need help. Some families manage just fine: they have the resources, the extended networks; they are able to pay for help. So it's really targeting those family members who are most at risk for emotional loss, for physical health issues, or the economic consequences of caregiving. These are the ones that need to be identified and targeted – those who could be helped by some caregiving services. It's figuring out through the workplace, faith communities, and other places how best to reach families and get the services to them.*
>
> *Create a Governor's task force to develop MN's statewide strategy & "Call to Action" for caregiver support – broadly include hospitals, clinics, community-based providers, faith-based organizations, funders, technology vendors, caregivers, researchers, unions/HR reps, etc. – having an on-going task force will keep the attention on it.*
>
> *Have MBA and/or AAAs to work with health plans who offer any kind of Medicare product (e.g., Medicare Advantage, Special Needs Plans, etc.) to disseminate information to family caregivers, as well as having them create incentives to have their members use caregiver support services.*

Appendix H: Key informant interview guide

Title III-E National Family Caregiver Support Program Survey

Thanks for taking the time to talk with me today. My name is ___________and I work for Wilder Research. We are helping the Minnesota Board on Aging with their review of the family caregiver services offered through Title III-E of the Older Americans Act. We are hoping that you can add your thoughts to the conversation. The purpose of this evaluation is to review the status of the current Title III-E NFCSP, to identify current trends, research and best practices for supporting caregivers, and explore opportunities for future work. Key informant interviews are being conducted to gather information and perspectives on what might be done to improve outreach so that these programs get to the people who need them, as well as to improve the programs to make them as useful as they can be to the many caregivers in our state.

The interview is voluntary. Any information you share will be kept confidential. However, I will ask you at the end of the interview if you are willing to have your comments and observations attributed to you so that they could be shared more easily with other program leaders involved in this initiative.

The interview takes about 20 minutes, depending on how much you have to say in response to our questions.

Is now still a good time to talk? ____Yes ____ No   Shall we begin? ____Yes ____ No

1a. First, for the record, could you please tell me your organizational affiliation?

1b. Could you please also tell me your title or position within your organization?

2. And could you tell me if your current experience in working with caregivers includes: (check all that apply)
    a. ___Direct service to caregivers as a paid staff
    b. ___Direct service to caregivers as a volunteer
    c. ___Acting as an unpaid caregiver to an older adult yourself
    d. ___Caregiver program management
    e. ___Caregiver program planning and development
    f. ___Research or evaluation regarding caregivers and their service needs or use
    g. ___Allocating funds for caregiver services
    h. ___Other (please specify___________________________________)

As you probably know, Title III-E funding for supporting family caregivers was added to the Older Americans Act in the year 2000. The federal appropriation for Title III-E is about 150 million dollars per year. This funding is allocated to states who award it to their local Area Agencies on Aging. Area Agencies on Aging award regional funding via grants or contracts to direct service providers who support family caregivers. Different states use the money in different ways. In fact, in some states, most of this money is used to help grandparents raising grandchildren. But in Minnesota, it is mostly used to help caregivers serving older adults. All states are required to offer the following services:

- information to caregivers about available services,
- assistance to caregivers in gaining access to the services,
- individual counseling, organization of support groups, and caregiver training,
- respite care, and
- supplemental services, on a limited basis

Minnesota service definitions/examples, as needed:

1. INFORMATION SERVICES ---provide information on resources and services available to caregivers
2. ACCESS ASSISTANCE—assist caregivers with information, connections to resources, and follow-up
3. COUNSELING—individual or family counseling; coaching and consultation with a comprehensive assessment; support groups; group training and education to provide caregivers with knowledge, skills, and tools
4. RESPITE CARE-- Services that offer temporary, substitute care, supervision, support, or living arrangements to older persons in order to provide a brief period of relief or rest for informal caregivers
5. SUPPLEMENTAL SERVICES—Additional services to ease the burden of caregiving or assist with caregiving responsibilities may include chore/homemaker, transportation, legal assistance or education, special access for minority and non-English speaking older adults]
6. <u>Self-Directed Service grants</u>: Budget amount provided to high risk caregivers for goods or services, or to hire workers. Provides flexibility/choice/control. Fiscal support entity helps manage the budget and financial functions. AAAs screen caregivers, set the budget, work with caregiver to develop plan, refer to FSE. Currently used for respite, meals, transportation.

For AAAs only

The Minnesota Board on Aging allocates Title III-E OAA funding to seven Area Agencies on Aging for supporting family caregivers. The Title III-E funding has been relatively flat.

[2014: $2,019,103; 2015: $2,017,435; and 2016: $2,074,119]

3. Based on your experience, do you think Minnesota is using the current Title III-E funds in a way that best achieves the goals of the program?

4. If Title III-E allowed greater flexibility in how dollars are spent, are there areas where you could see providing services outside the current funding boundaries?
   a. Yes→ Could you say a little more about that? [Probe: Can you talk about some of the specific ways in which you think the funds are being best or most effectively used?]
   b. No→ What would you do differently? [Probe: If Title III funding allowed greater flexibility in how dollars are spent, where could you see stretching outside the current funding boundaries?]

5. Each year, some of the Title III-E funds are not used. That is, we don't spend all of the money available. Do you have any thoughts about how we might improve the utilization of these funds and services?

Now I have a few questions about self-directed grants.

6. Is [your agency] providing self-directed grants?

   a. Yes→ Do you think this option has been successful in addressing an unmet need? Why or why not?

   b. No→ Do you think that family caregivers would be interested in self-directed grants that allow them to purchase care-related goods or supplies to hire their own workers?

7. If self-directed grants were targeted to high-risk caregivers during transitions of care with support from staff and a fiscal support entity, would you anticipate more interest from caregivers in using the self-directed option? [Probe]

8. In your experience, what do you think is the general level of awareness of services among caregivers?

   a. Do caregivers know what services exist?

   b. If caregivers know what services exist, do they know how to access them?

9. Do you have any ideas for improving awareness of the services available through the Title III-E program?
    a. How do we best "get the word out" to caregivers about the services that are available to them?
    b. How do we help people with access to these services?
10. When you think about outreach to caregivers, do you have any suggestions for how best to engage caregivers?
    a. Do you have any suggestions for where to best connect with them?
    b. What might be offered in the early stages of their caregiving to encourage caregivers to consider using services?
11. Do you have thoughts about how to reduce the resistance that some caregivers feel toward using caregiver services like respite care, support groups, coaching, or training?
12. When you think about people you know who are caregivers, what kinds of help or support do you think makes the most difference in their lives? [Probe: Specific types of supports. Probe: What is it about these that make a difference?]
13. Do you know of specific caregiver programs or service models that, in your experience, are especially effective? What is it about these programs that you think do a particularly good job of meeting caregivers' needs?

[If NOT already asked of AAA respondent above] Do you think that family caregivers would be interested in self-directed grants that allow them to purchase care-related goods or supplies or to hire their own workers?

13a. Finally, thinking very broadly, even beyond any connection with Title III-E funding for programs, what do <u>you</u> think is the single biggest barrier to caregivers getting services for themselves?

b. What do <u>you</u> think could be done to reduce this barrier or to better engage and serve caregivers? [Probe: What changes or innovations could be implemented?]

14. Is there anything else you think we should know or anything else you would like to add? [Probe: systems changes?]
15. **[If noted on contact list]** Could you suggest to me one or two (providers/policy makers) you think we should talk to in order to be sure to sample a broad range of (experiences with/viewpoints on) the topics we have covered during our interview today? [Suggest emailing names to interviewer]

Those are all the questions I have for you. Thank you for taking the time to speak with me today.

We appreciate your perspective and insights. Could we call back to clarify anything we have discussed today? _____Yes _____ No

And, as we complete our report, are you willing to have your comments and observations attributed to you in order to facilitate communication with other program leaders?

_____Yes _____ No

Appendix I: References

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