



CHRT

A REPORT TO THE MICHIGAN HEALTH ENDOWMENT FUND

Scan of Family and Informal Caregiver Programs in Michigan

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AND RESEARCH
TRANSFORMATION

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Executive summary

Background

Michigan's population, like the rest of the United States, is aging rapidly. As a result, the number of family and informal caregivers in Michigan has increased substantially over the last three decades.

In recent years, policymakers and decision leaders have recognized the critical role of unpaid family and informal caregivers. These caregivers safeguard the health of our state's vulnerable populations—young and old alike—while also saving taxpayer dollars.

Policymakers and decision leaders have also become increasingly aware that caregiver stress can have a negative impact not only on caregivers and care recipients, but also on society.

As such, dozens of programs have been developed to support, educate, and assist caregivers. But the reach and efficacy of these programs has been difficult to assess. Understanding the most effective caregiver support programs is critical for caregivers who wish to participate in the best programs, but also to funders who wish to be more strategic with their funding and to policymakers who wish to scale up evidence-based solutions.

On behalf of the Michigan Health Endowment Fund, the Center for Health and Research Transformation (CHRT) has conducted a scan of family and informal caregiver support programs to better understand:

- the reach, efficacy, and evidence of caregiver support programs, as documented in practical and scholarly literature;
- the caregiver population in Michigan and the characteristics of those who do and don't engage in the state's caregiver support programs;
- the capacity of Michigan-based caregiver support programs to meet the needs and demands of the state's family and informal caregivers;
- the strengths and challenges of implementing current programs in Michigan; and
- the ways that family and informal caregiver support programs could be improved through informed grant making.

Key findings

- Approximately 23 percent of adult Michiganders (1.73 million) provide unpaid care to another adult.
- Although the largest shares of Michigan's caregivers are concentrated in more populated areas of the state, the percentage of adults who are caregivers is fairly consistent across the state.
- Caregiver support programs most often provide psychoeducational support, technical support, skill-building support, or a combination of these. Interventions that combine a range of supports and those that offer multiple delivery methods (phone, e-mail, in-person) seem better able to help caregivers.
- A considerable proportion of caregivers are not being reached by Michigan's current caregiver programs and services, including younger caregivers, male caregivers, and caregivers of color.

- While organizations across Michigan generally indicate that they are able to meet the needs of caregivers who actively reach out for assistance, organizations are likely missing a large number caregivers who do not reach out, who are unaware of available community supports, or who don't see themselves as 'caregivers.'
- There is a need for programs to recruit caregivers who have not traditionally participated in support programs. This is especially true for Black, Indigenous, and people of color (BIPOC) caregivers, male caregivers, and those who are employed (and particularly those who also have children).
- Future work is needed to overcome barriers to gathering and reporting racial and ethnic data, as well as to identifying strategies to encourage complete reporting of demographic information. This data is essential to identifying best practices and scaling-up effective interventions.
- During COVID-19, many caregiver support programs were halted due to restrictions on in-person gatherings. At the time of our research, only a small number of programs had been adapted for online delivery.

Our recommendations

1. **Raise awareness.** Launch a large-scale awareness campaign to reach people who do not recognize that they are caregivers. Educate these individuals about their role, the importance of self-care, evidence-based care strategies, and helpful support programs.
2. **Collect data.** Standardize data collection measures to better inform decision-making and continuous quality improvements. Ensure that this data can be reported by geography (census tract or zip code) by race/ethnicity, by program delivery method, by session length, and by care recipient health condition.
3. **Ensure equitable access.** Make it easier for marginalized groups to learn about and enroll in support programs and ensure that programs are diverse, equitable, and inclusive, reaching and welcoming all who need them, regardless of race, ethnicity, gender expression, or ability to pay.
4. **Improve access.** Support AAAs and other caregiver support organizations as they expand program delivery options (in-person, online, by phone, by chat, etc.) post-pandemic. Improving high-speed internet access is critical to reaching caregivers in need of support and promoting equitable access to caregiver services.
5. **Expand reach.** For example, work to increase workforce capacity, improve pay for direct care workers, offer more training opportunities. Expand respite services to overcome barriers to participation. Without the ability to provide caregivers with relief, engagement in support programs and services will be limited.
6. **Fund wisely.** Expand funding specifically for caregiver-related support programs and services in order to increase opportunities for caregivers to engage in programs and overcome logistical barriers to participation. Also prioritize funding for programs that use partnerships to meet people where they are and technology to improve engagement and uptake of caregiver support programs.
7. **Monitor progress.** Create a state task force to gather, update, and disseminate information about evidence-based programs, best practices, evaluation measures, and tools. Find ways to advocate for sustainable change through legislative or administrative supports.
8. **Develop partnerships.** Expand the reach of caregiver supports by developing new collaborations with health systems, hospitals, universities, AARP, the Alzheimer's Association, and other stakeholders.

Background

There are approximately 48 million individuals in the United States providing unpaid care to adult family members, friends, or neighbors. Of these, 41.8 million, or 87 percent, have provided unpaid care to an adult age 50 years or older in the last 12 months.ⁱ These individuals—who run errands, help out financially, provide transportation, and much, much more—are often called “family caregivers” or “informal caregivers.” Typically, these activities are unpaid.

The AARP Public Policy Institute estimated the economic value of unpaid caregiving at approximately \$470 billion in 2017.ⁱⁱ For reference, this value is greater than all out-of-pocket spending on health care in the U.S. in 2017 (\$366 billion) as well as the combined spending from all payers on long-term services and supports, including post-acute care, in 2016 (\$366 billion).

Recent studies suggest a growing reliance on family caregivers. According to a report by the National Alliance for Caregiving and AARP, the prevalence of Americans who provide unpaid care to an adult has increased significantly from 16.6 percent in 2015 to 19.2 percent in 2020. This increase has been attributed to factors such as the aging baby boomer population and new state policies that facilitate home-and community-based services.

In light of the COVID-19 pandemic, family caregivers have also reported an increase in the amount of care that they provide. According to a survey by the National Rehabilitation Research and Training Center on Family Support and the University Center for Social and Urban Research at the University of Pittsburgh, more than half (63 percent) of family caregivers reported that their caregiving efforts and duties had increased due to the pandemic.ⁱⁱⁱ

Within the context of Michigan, demographic trends also suggest a growing demand for family caregivers. The number of Michiganders eligible for services under the Older Americans Act and the Older Michiganians Act is increasing by an estimated 62,000 per year. This population growth has outpaced that of other age groups, and in many counties the number of residents 65+ surpasses the number of residents under the age of 18.^{iv} As the population of older adults in Michigan increases rapidly relative to younger age groups, the need for services that support older adults and their family caregivers is also projected to grow.

While caregiving can offer certain benefits to caregivers, such as providing a sense of purpose, it can also have negative impacts. Studies show that family caregivers often have higher rates of depressive symptoms, anxiety, stress, and emotional difficulties when compared to non-caregivers.^v These psychological effects can lead to poor physical health for the caregiver as well as the care recipient.^{vi}

Between the caregiver and the care recipient, there often exists a dyadic relationship. This means that the state of one can impact the other. Research shows that care recipients are more likely to report poor self-efficacy, treatment adherence, and symptom monitoring when their caregivers are experiencing anxiety, depression, or stress.^{vii}

Additionally, when caregivers report greater benefits than burdens from caregiving, their recipients are less likely to become depressed than those receiving care from individuals that report mostly burdens. These findings highlight the need for effective, accessible programs to support caregivers, and their care recipients in turn.

Purpose

On behalf of the Michigan Health Endowment Fund, the Center for Health and Research Transformation (CHRT) conducted a scan of family and informal caregiver support programs to better understand:

- the reach and efficacy of caregiver support programs, as evidence is documented in practical and scholarly literature;
- the caregiver population in Michigan and the characteristics of those who do and don't engage in the state's caregiver support programs;
- the capacity of Michigan-based caregiver support programs to meet the needs and demands of the state's family and informal caregivers;
- the strengths and challenges of implementing current programs in Michigan; and
- the ways that family and informal caregiver support programs could be improved through informed grant making.

In order to accomplish these goals, CHRT utilized a multipronged approach that included:

1. reviewing peer-reviewed, white, and grey literature to assess the landscape of family and informal caregiver support programs available and to categorize these programs based on levels of evidence;
2. developing population estimates for family and informal caregivers in Michigan;
3. analyzing data on caregiver programs and services to better understand who is engaging in these supports across the state; and
4. collecting and analyzing data from Michigan-based organizations (through interviews and surveys) to better understand the programs currently being implemented, staff capacity and ability to meet demand, barriers to engaging caregivers in programs, and the impact of COVID-19 on caregivers and programming.

Literature review

Background

CHRT's literature review built on research, conducted by the Benjamin Rose Institute (BRI), on best practices in caregiving. Because the BRI had already provided substantial evidence surrounding programs for individuals caring for someone with dementia through its Best Practice Caregiving Initiative^{viii}, CHRT's review placed a greater focus on health conditions other than dementia, which would require caregiver support programs not tailored to a given health condition. The goal of CHRT's review was to explore studies regarding family caregiver programs and best practices. For each study, the following information was summarized:

- caregiver support program descriptions;
- descriptions of the caregivers who participate in these programs;
- descriptions of the caregivers who do not participate in these programs;
- best practices noted in the study for outreach, promotion, engagement, and retention;
- participation rates, data tracked, and outcomes documented;
- types of programs (or services) caregivers indicated that they wanted or needed

- types of services or features that were most utilized by participants; and
- other key features, as warranted.

Evidence levels

CHRT developed a three-tier rubric to classify caregiver programs based on the rigor of evidence employed during program design: Level 1: evidence-based programs, Level 2: evidence-informed programs, and Level 3: innovative/developing programs.

Level 1 programs: Using program eligibility criteria based on the Benjamin Rose Institute’s Best Practice Caregiving Initiative^{ix}, Level 1 programs had:

- one or more randomized or non-randomized controlled trial was employed, or a pre/post-test study with no control group was employed as a basis for evidence;
- research conducted in the United States with at least one statistically significant, published, beneficial caregiver outcome;
- been implemented one or more times as part of an organization’s regular service portfolio.

Level 2 programs: Programs developed using descriptive or qualitative studies were labeled Level 2.

Level 3 programs: Programs that were relatively new and untested, but relied on evidence from expert opinions, were labeled Level 3.

Methods

For this review, PubMed and Google Scholar were used to conduct searches of existing academic literature. Using the terms “family caregiver” and “program,” and excluding non-peer-reviewed articles, 223 results were returned. Of these results, 150 were screened for inclusion based on the eligibility criteria established by the BRI. Using the search terms (family or informal), “program”, and “caregiver (in title),” in PubMed only, 429 results were returned. Of these, 65 screened for inclusion based on the eligibility criteria established by the BRI.

A grey literature search was also conducted using Google to expand the pool of included programs. To determine the evidence base for programs identified through the grey literature search, the name of the program was entered as a keyword in PubMed and Google Scholar. If no empirical literature was found outlining caregiver outcomes for the program, then the program was classified as a Level 3 program.

Findings

Caregiver characteristics^{x,xi}

Caregiver demographics. Individuals between the ages of 55-64 most commonly provide unpaid care (24 percent), followed by 45-54 year-olds (21percent), and individuals 65 years and older (18 percent). Age tends to increase as hours per week spent caregiving increases. Approximately 39 percent of all family caregivers are male, although estimates vary.

Race/ethnicity. White caregivers make up 61 percent of the caregiving population, followed by African-American caregivers at 14 percent, Hispanic (non-white, non-African-American) caregivers at 17 percent, and Asian-American caregivers at 5 percent. Hispanic (non-white, non-African-American) caregivers have the highest prevalence of

caregiving among racial/ethnic groups at 21 percent. Among African-Americans and Asian-Americans, the prevalence for both groups is approximately 20 percent. White caregivers have the lowest prevalence of caregiving at 17 percent.

Caregiver responsibilities. About three out of four caregivers provide care for one other adult, while 19 percent care for two and 5 percent care for three or more adults. Unemployed caregivers provide more hours of care than employed caregivers. Unemployed caregivers put in 4.1 hours, on average, on days they provide care while employed caregivers averaging 2.3 hours on the weekdays they provide care and 3.3 hours on the weekends. Over 8 million family caregivers have children living at home. Of these, more than 30 percent have a child under the age of six. Most caregivers who are parents are also employed (82 percent). Full-time workers account for 69 percent of this subgroup. Caregivers with children are less likely to provide daily care than childless caregivers (12 percent vs. 21 percent). However, both groups are equally likely to provide care several times a week. Almost 40 percent of caregivers are caring for someone who is 85 years or older. Approximately 32 percent of those caring for someone 65 years and older are caring for someone who has Alzheimer's disease or another form of dementia.

Family caregiver programs

There are many programs in the United States and around the globe that support family caregivers. Most of these programs provide caregivers with training, resources, or social and emotional supports. Programs often include education about specific health conditions, training in needed skills, caregiver coping strategies and stress management tactics, connections to support groups, and respite care. Programs are also frequently tailored to specific health conditions because educational and support needs often differ based on a care recipient's condition. Program delivery methods vary, as well: most commonly, programs are offered either in-person, online, or via telephone. As the characteristics, lifestyles, and preferences of caregivers vary widely, some program delivery formats may be better suited to some caregivers, and less appealing to others.

Family caregiver program participant characteristics

Caregivers who participated in the previously mentioned studies ranged from 52 years old to 66 years old. On average, they were The vast majority of caregiver support program participants were white (85 percent), with African-American participants making up 12.1 percent. Females made up a larger portion of the study participants than males, accounting for almost 80 percent of participants. This trend is seen throughout the literature and indicates a very high need for research that reaches those in minority populations and male caregivers. Caregivers were most often the spouse (40 percent) or the adult child (370 percent) of their care recipient. Although details about caregiver education level were not included in several studies, among the data that is available, most caregivers in the reviewed programs had some education beyond a high school degree (76 percent).

Family caregiver programs based on levels of evidence

Table 1.

Level 1, evidence-based caregiver programs

Program name	Delivered by	Delivery method	Session length	Program length	Program description	Program impact	Care recipient health condition
A Brief Behavioral Sleep Intervention for Family Caregivers of Persons with Cancer^{xii}	Research nurses	In-person delivery	1 hour	Four months	The individualized Caregiver Sleep Intervention (CASI) consists of multiple one-hour sessions to support the restful sleep of family caregivers. CASI covers relaxation techniques, cognitive therapy, stimulus control, and sleep hygiene elements.	Caregiver outcomes include improvements in sleep quality, fewer depressive symptoms, and greater quality of life.	Cancer
Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS)^{xiii}	Professional or paraprofessional	In-person delivery; telephone delivery	1.5 hours	Six weeks	ANSWERS include ixix in-person, individualized education and skills-training sessions for caregivers and persons living with dementia, focused on practical coping strategies and managing symptoms based on cognitive rehabilitation principles.	Caregiver outcomes include fewer symptoms of depression and anxiety, less care-related strain, less strain in caregiver relationship with care recipient, and increased caregiver mastery.	Alzheimer's/ Dementia
Alzheimer's Disease Coordinated Care for San Diego Seniors (ACCESS)^{xiv}	Professional or paraprofessional	In-person delivery; telephone delivery	Varies	Varies	ACCESS is an ongoing (in-person or telephone) individual care coordination program for caregivers	Caregiver outcomes include greater use of community services and supports,	Alzheimer's/ Dementia

					and persons living with dementia, focused on identifying problems, planning actions, and linking to community services and resources.	greater confidence in care and caregiver mastery, fewer unmet needs, and more social support. Care recipient outcomes include better quality care and smaller declines in patient health-related quality of life. Provider outcomes include better dementia knowledge, skills, and competencies.	
Benjamin Rose Institute on Aging (BRI) Care Consultation™ ^{xv}	Professional or paraprofessional	Telephone delivery; email delivery	Varies	Minimum of three months	Ongoing (telephone and email) individual care-coaching for caregivers and persons living with dementia and/or other chronic conditions, focused on accessing community and family resources, obtaining quality information, and providing emotional support.	Caregiver outcomes include fewer depressive symptoms, less care-related strain, decreased physical health strain, less strain in caregiver relationships with the care recipient, decreased isolation, more social support, fewer unmet needs, increased confidence in care; and increased support service use.	Alzheimer's/ Dementia

						Care recipient outcomes include fewer depressive symptoms, decreased embarrassment about memory problems, decreased unmet needs, increased informal supports, and increased community service use.	
Building Better Caregivers^{xvi}	Lay leader	In-person delivery	2.5 hours	Six weeks	Six in-person, group education sessions for caregivers, focused on techniques for reducing stress, action planning, problem-solving, and decision-making.	<p>Caregiver outcomes include fewer depressive symptoms, decreased caregiver strain, increased caregiving self-efficacy, better physical health.</p> <p>Care recipient outcomes include reduced emergency department and primary care visits.</p>	Alzheimer's/ Dementia
Building Better Caregivers Online Mode^{xvii}	Lay leader	Online delivery	2 hours	Six weeks	Online, group education sessions for caregivers, focused on techniques for reducing stress, action planning, problem-solving, and decision-making.	Caregiver outcomes include fewer depressive symptoms, reduced caregiver stress and burden, increased caregiving self-efficacy, reduced	Alzheimer's/ Dementia

						<p>pain, and increased exercise.</p> <p>Care recipient outcomes include better physical health</p>	
Creating Confident Caregivers^{xviii}	Lay leader or professional or paraprofessional	In-person delivery; online delivery	2 hours	Six weeks	<p>Psychoeducational intervention to enhance family caregiver knowledge, skills, and attitudes to support them as they care for someone with Alzheimer's or another form of dementia. Based on the Savvy Caregiver program.</p>	Caregiver outcomes include enhanced caregiver skills, outlook, and self-care	Alzheimer's/ Dementia
The Family Intervention: Telephone Tracking—Caregiver (FITT-C)^{xix}	Masters level therapist	Telephone delivery	15-60 minutes		Caregiver engagement was successfully increased by the use of this program.	Caregiver outcomes include increased caregiver engagement	Alzheimer's/ Dementia
The Family Series Workshop: A Community-Based Psychoeducational Intervention^{xx}	Health care professional	In-person delivery	90 minutes	Six months	The FITT-C intervention provided psychoeducation, problem solving, and other directive approaches based on assessment of critical areas (e.g., mood, behavior, family functioning, social support).	<p>Caregiver outcomes include significantly improved competence and a marginal, positive impact on coping with humor. Coping through positive reframing, religion, self-distracting, and venting approached statistical significance</p> <p>Caregiver stress levels were not</p>	Alzheimer's/ Dementia

						significantly impacted	
FOCUS Program^{xxi}	Professional	In-person delivery; telephone delivery	90-minute home visits; 30-minute telephone sessions	Five weeks	Couples-based intervention delivered through either an extensive version (four home visits, one telephone call) or a brief version (two home visits, one telephone call). The core foci of the program include family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management.	Couple outcomes include improved quality of life, reduced emotional distress, and improved self-efficacy.	Cancer
Mindfulness Training for Patients with Progressive Cognitive Decline and their Caregivers Program^{xxii}	Professional or paraprofessional	In-person delivery	1.5 hours	Eight weeks	Eight in-person, group meditation and mindfulness sessions for caregivers, focused on movement meditation and yoga.	Caregiver outcomes include fewer depressive symptoms, improved quality of life, improved physical health, and improved emotional health. Care recipient outcomes include fewer depressive symptoms, improved quality of life.	Alzheimer's/ Dementia
Mindfulness-Based Alzheimer's Caregiving	Lay leader, professional, or paraprofessional	In-person delivery	2 hours	Eight weeks	Eight in-person, group mindfulness sessions for caregivers, focused	Caregiver outcomes include fewer depressive	Alzheimer's/ Dementia

Program ^{xxiii}					on mindful movement, meditation, and mindful communication.	symptoms, reduced caregiver stress and burden, improved mood, improved mental functioning, and improved physical functioning	
Mindfulness-Based Stress Reduction for Dementia Caregivers ^{xxiv}	Lay leader	In-person delivery	2.5 hours	Eight weeks	Eight in-person, group mindfulness sessions, focused on meditation techniques and mindful Hatha yoga.	Caregiver outcomes include reduced depression and anxiety, reduced perceived stress and burden, improved social support, and better physical health.	Alzheimer's/ Dementia
New Ways for Better Days: Tailoring Activities for Persons with Dementia and Caregivers (TAP) ^{xxv, xxvi, xxvii}	Professional or paraprofessional	In-person delivery; telephone delivery	30 - 60 minutes	Varies	Up to 11 (in-person and telephone depending on context or care delivery) individual skills-training sessions for caregivers, focused on activities aligned with interests and capabilities of persons living with dementia to prevent or reduce behavioral symptoms and address functional dependence or functional decline.	Caregiver outcomes include reduced care-related burden, improved caregiver confidence and mastery, cost-effectiveness of the intervention. Care recipient outcomes include reduction in behavioral symptoms, increased activity engagement and satisfaction.	Alzheimer's/ Dementia
New York University Caregiver Intervention (NYUCI) ^{xxviii}	Professional or paraprofessional	In-person delivery; online delivery	1 - 1.5 hours	Four months with ongoing consultation as needed	Six in-person, individual and group counseling and support sessions for	Caregiver outcomes include fewer depressive symptoms, greater	Alzheimer's/ Dementia

					caregivers and other family members, focused on strengthening family and friend support, addressing caregiver needs, and improving interactions among the family members.	quality of life/life satisfaction.	
Online Support for Employed Informal Caregivers^{xxix}	Nurse or peer-led	Online delivery	Varies	12 weeks	Caregivers were divided into a professionally facilitated psychoeducational group and a moderated/peer-directed group, both with different webpages for caregivers to access and interact with. The professional-led group followed a structured format with topics chosen based on research. The moderated group ran in a self-help format with no weekly topics or agendas.	Significant differences in depression symptoms between non-active and active participants, but not between intervention groups. Similarly, quality of life scores decreased over the study period for non-active participants but increased for active participants.	Any
Powerful Tools for Caregivers (Powerful Tools)^{xxx}	Lay leader, professional, or paraprofessional	In-person delivery	1.5, 2, or 2.5 hours per week	Six weeks	Six in-person, group self-care education sessions for caregivers of persons living with dementia and/or other chronic conditions, focused on tools for reducing stress,	Caregiver outcomes include reduced depressive symptoms and reduced care-related stress, strain, or burden.	Alzheimer's/Dementia and other chronic conditions

					promoting effective communication, managing emotions, and decision making.		
Powerful Tools for Caregivers—Telehealth^{xxxi}	Lay leader Professional or paraprofessional	Online delivery	90-minute class sessions; 30 to 60 minute software training session	Six weeks	Six group education sessions delivered synchronously using videoconferencing software. Sessions focus on tools for reducing stress, promoting effective communication, managing emotions, and decision making. Participants also receive training on how to use videoconferencing software.	Caregiver outcomes include reduced depressive symptoms	Alzheimer's/Dementia and other chronic conditions
REACH Community (Resources for Enhancing Alzheimer's Caregivers in the Community)^{xxxii}	Lay leader Professional or paraprofessional	In-person delivery; telephone delivery	1 hour	–Eight to 12 weeks	Four (in-person or telephone) individual education and skills-training sessions for caregivers, focused on care planning, understanding the injury or illness of the person needing care, problem-solving, and stress management.	Caregiver outcomes include reduced depressive symptoms and increased caregiver quality of life/life satisfaction	Alzheimer's/ Dementia
REACH TX^{xxxiii}	Professional or paraprofessional	In-person delivery; telephone delivery	N/a	Six months	Four individual, education and skills-training sessions for caregivers and persons living with dementia, focused on an array of potential problems,	Reduced caregiver symptoms of depression. Improved caregiver quality of life/life satisfaction.	Alzheimer's/ Dementia

					such as home safety, stress management, positive activities, and managing behavioral symptoms.		
REACH VA (Resources for Enhancing All Caregivers Health in the VA)^{xxxiv}	Lay leader, professional, or paraprofessional	In-person delivery; telephone delivery	1 hour	–Eight to 12 weeks	Four (in-person or telephone) individual education and skills-training sessions for caregivers of veterans living with dementia, focused on care planning, understanding the injury or illness of the person needing assistance, problem-solving, and stress management.	Reduced caregiver symptoms of depression. Improved caregiver quality of life/life satisfaction.	Alzheimer's/ Dementia
Reducing Disability in Alzheimer's Disease (RDAD)^{xxxv}	Professional or paraprofessional	In-person delivery	1 hour	Five months	12 in-person, individual or group exercise training and education sessions for caregivers and persons living with dementia, focused on gentle exercise for the person with dementia, and caregiver training to manage behavioral symptoms and identify pleasant events.	Reduced caregiver symptoms of depression.	Alzheimer's/ Dementia
Savvy Caregiver^{xxxvi}	Lay leader, professional, or paraprofessional	In-person delivery	2 hours	Six weeks	Six in-person group education and skills-training sessions for caregivers, focused on enhancing caregiving knowledge and skills,	Caregiver outcomes include fewer depressive symptoms, improved caregiver quality of life/life	Alzheimer's/ Dementia

					coping with stress, and encouraging persons living with dementia to participate in daily tasks and activities.	satisfaction.	
Tele-Savvy^{xxxvii}	Lay leader, professional, or paraprofessional	Online delivery	Seven 75-90 minute synchronous group sessions; 36 brief asynchronous video lessons	Seven weeks	An online psychoeducation program for family caregivers modelled after Savvy Caregiver. The program features both synchronous group sessions and asynchronous video lessons.	Caregiver outcomes include reduced depressive symptoms and perceived stress, improved caregiver mastery.	Alzheimer's/ Dementia
Skills2Care^{xxxviii}	Professional or paraprofessional	In-person delivery, telephone delivery, online delivery	90 minutes - in home; 30 minutes - telephone	—One to four months	Eight to 12 in-person, individual education and skills-training sessions for caregivers, focused on managing behavioral symptoms, slowing functional decline of persons living with dementia, and coping with caregiver stress.	Reduced care-related stress, strain, or burden. Improved efficacy, skills, or confidence in caregiving and/or symptom management Family/friend support for caregiver - quantity	Alzheimer's/ Dementia
STAR Caregiver (STAR-C) *Tele-STAR option^{xxxix}	Lay leader	In-person delivery, telephone delivery	1 hour	Six weeks	Six (in-person and telephone) individual education and skills-training sessions for caregivers and persons living with dementia, focused on reducing behavior problems in dementia, communication, caregiver support, and pleasant events.	Reduced caregiver symptoms of depression. Reduced care-related stress, strain, or burden.	Alzheimer's/ Dementia

Stress-Busting Program for Family Caregivers^{xi}	Lay leader	In-person delivery, online delivery	1.5 hours	Nine weeks	Nine in-person, group education sessions for caregivers, focused on tools and strategies for self-care, techniques for coping with stress, and problem-solving.	Reduced caregiver symptoms of depression. Improved quality of life/life satisfaction.	Alzheimer's/ Dementia and other chronic diseases
Stroke Caregiver Outcomes from the Telephone Assessment and Skill-Building Kit (TASK)^{xli}	Nurse	Telephone delivery	Varies	Eight weeks	Eight weekly calls to go over a weekly assessment of skill needs using a caregiver Needs and Concerns Checklist (CNCC)	At four, eight, and 12 weeks, there were significant increases in optimism among participants. There was also significant improvement in task difficulty at four weeks, and threat appraisal at eight and 12 weeks	Stroke
Telehealth Education Program for Caregivers of Individuals with Dementia^{xlii}	Professional or paraprofessional	Telephone delivery	Varies	12 weeks	Ten telephone, individual education sessions for caregivers of persons living with dementia, focused on basics on dementia, behavioral symptoms, communication, planning for the future, and coping.	Reduced care-related stress, strain, or burden.	Alzheimer's/ Dementia
TCARE (Tailored Caregiver Assessment and Referral)^{xliii}	Professional or paraprofessional	In-person delivery, telephone delivery	1 hour	Ongoing	Ongoing in-person or telephone, individual care-management and support program for caregivers of persons living with dementia and/or other chronic conditions, focused on	Improved caregiver well-being: Symptoms of depression; care-related stress, strain, or burden; Quality of relationship with	Various

					assessment, care planning, and accessing community resources.	person with dementia. Support for caregiver: Provide support, information, community service use.	
UCLA Alzheimer's and Dementia Care (UCLA ADC)^{xliv}	Professional or paraprofessional	In-person delivery, telephone delivery, online delivery, email delivery	Varies	Ongoing	Ongoing (in-person, telephone, email, and online) individual dementia care management for caregivers and persons living with dementia, focused on medical, behavioral, and social needs.	Reduce/improve caregiver symptoms of depression, Care-related stress, strain, or burden PWD symptoms of depression, Symptoms severity, difficulty, or distress.	Alzheimer's/ Dementia
WeCareAdvisor^{xlv}	Electronically delivered; automated	Online delivery	N/A	N/A	Web-based tool (for iPad) created for family caregivers to assess, manage, and track behavioral and psychological symptoms of dementia (BPSD). Guides caregivers through a clinical reasoning process so they can track and understand the behaviors of their care recipients.	Caregiver distress decreased significantly, but impact on caregiver confidence was not clear. Caregiver burden as well as negative communication and behavioral frequency also saw no significant change.	Alzheimer's/ Dementia

Table 2.

Level 2 evidence-informed caregiver programs

Program name	Delivered by	Delivery method	Session length	Program length	Program description	Program impact	Care recipient health condition
Aging Mastery Program for Caregivers^{xlvi}	Trained leaders	In-person delivery	90 minutes	12 classes	This 12-part class educates caregivers about the impacts of caregiving and also provides them with the tools they need to stay healthier and happier in the caregiving journey. The program consists of the standard AMP core curriculum bookended with two classes specifically designed to address caregiver concerns.	Improved or enhanced: Social connectedness Physical activity levels Healthy eating habits Use of advanced planning Participation in evidence-based programs Adoption of several other healthy behaviors.	Various
Caregiver Café^{xlvi}	Nurse	In-person delivery	1 hour	Ongoing	Every caregiver and patient, if present, is offered a cup of coffee, tea, or cocoa and a snack. They are then asked how they are doing and if there is anything they need. Caregivers are introduced to each other and encouraged to interact with each other. The format ranges from a guided coffee break to group discussion to individual counseling, depending on the caregiver's needs. A display rack with caregiver-specific materials is also available at the cafe location to supplement discussions and provide answers and resources when the cafe is not in session or caregivers are unable to attend.	Caregivers verbalized the importance of the café in helping them cope with their loved one's cancer and treatment.	Cancer
Caring for Others^{xlvi}	Health care professional	Online delivery	1 hour	Ten weeks	Therapeutic support is provided by focusing on helping group members understand how personal styles for regulating emotions and processing information either advanced or thwarted caregiving role functions.	The intervention proved successful with a decline in stress compared with an escalation in stress for the control group.	Neuro-degenerative Disease
Caring~Web^{xlvi}	Electronically delivered	Online delivery	Varies	One year	An online program including four interrelated components for	This Web-based intervention helped new caregivers make	Stroke

					caregivers: (1) linked websites about stroke and caring; (2) customized educational information or tips specific to caregivers' needs; (3) an email forum to ask a nurse specialist and a rehabilitation team (therapist, pharmacist, dietitian, social worker, and physician) any questions in private and (4) a non-structured email discussion among all participants facilitated by the nurse.	informed decisions about the health care needs of stroke survivors, thus reducing service use.	
CHESS (Comprehensive Health Enhancement Support System)ⁱ	Electronically delivered	Online delivery	Varies	24 months	Web-based lung cancer information, communication, and coaching system for caregivers.	Reduced the caregiver burden and improved mood within the context of advanced cancer. on the program did not show a reduction in disruptiveness (the amount that caregiving duties interfere with a caregivers regular, daily activities).	Cancer
Family Informal Caregiver Stroke Self-Management (FICSS) Programⁱⁱ	Professional or paraprofessional	In-person delivery	2 hours	Eight weeks	The FICSS program is a four-module series. Each module is a two-hour small group guided discussion and problem-solving session on the topic area, guided by the needs of the group participants.	The program offered hope, advocacy, sharing, and the sense of being more informed about various topics including: coping skills, self-management, and how to access community service resources. As a result, participants felt more confident in their caregiving abilities and more at ease.	Stroke
Mindfulness-based stress reduction (MBSR) for Caregivers of Frail Elderly^{lii}	Professional or paraprofessional	In-person delivery	90 minutes	Eight weeks	The standard MBSR curriculum consists of weekly classroom meetings in which participants are (1) instructed regarding the background and rationale for using mindfulness exercises, (2) guided	Self-reported depression, perceived stress, and burden decreased during the eight-week intervention with further reduction demonstrated after a one-month follow-up	Frailty

					through specific techniques designed to promote and foster the experience of mindfulness in daily life, and (3) encouraged to complete specific daily homework exercises.	regarding stress and burden while depressive symptoms returned to baseline level.	
Self-Care Talk^{liii}	Nurse	Telephone delivery	30 minutes	12 weeks	A series of telephone-based sessions between advanced practice nurses and older adults. Session content includes practicing healthy habits, building self-esteem, focusing on the positive, avoiding role overload, communicating, and building meaning.	Study participants indicated that the dosing, format, and content of Self-Care Talk sessions were appropriate and useful. Participants also were pleased with the telephone format.	Alzheimer's/ Dementia
Trualta^{liv}	Case manager	Online delivery	Varies	Varies	A free online educational tool for family caregivers Trualta has a library of online resources. The modules teach caregivers how to safely provide hands-on care, connect families with reliable support agencies, and offer information and video training from experienced professionals in a quick and easy format.	White papers were requested but not provided.	Various

Table 3.

Level 3 innovative/developing caregiver programs

Program name	Delivered by	Delivery method	Session length	Program length	Program description	Care recipient health condition
ALS Care Connection^{lv}	User guided	Online delivery	N/A	Indefinite, offered on continuous basis	Online platform helps to coordinate volunteer activities for caregivers of someone with ALS, provide a space for members to offer words of support, encouragement, and post updates, and schedule caregiver respite volunteers.	ALS
Ahead of the Curve^{lvi}	User guided	Online delivery	N/A	Indefinite, offered on	Web-based program offers a searchable senior resource directory that includes county-wide resources for older adults,	Any

				continuous basis	online quizzes to help residents and caregivers get connected with resources, a blog, and interviews with local agencies that serve seniors.	
NextShift^{lvii}	Professional or paraprofessional	In-person delivery, online delivery	Varies	Indefinite, offered on continuous basis	Whole-person programming including classes, workshops, and one-on-one assistance. Family support coordinators meet with caregivers to develop a personalized plan. Areas of assistance include connections to community resources, relieving caregiver stress, long-term care planning, education, grief/loss counseling, and family mediation.	Any
Successful Aging through Financial Empowerment (SAFE) Caregiver Empowerment Program^{lviii}	Professional or paraprofessional	In-person delivery, online delivery	Varies	Indefinite, offered on continuous basis	SAFE connects with older adults and caregivers to build financial skills to prevent scams and provide assistance when recovering from a scam. The program provides one-on-one coaching and workshops. Topics for family caregivers include difficult conversations around finances, managing someone else's money, and protecting loved ones from scams.	Any
Catching Your Breath^{lix}	Professional or paraprofessional	In-person delivery, online delivery	1.5 hours	Indefinite, offered on monthly basis	Free monthly program for learning and practicing stress resilience skills for continued health, balance and well-being.	Any
Calm Connections^{lx}	Professional or paraprofessional	In-person delivery, online delivery	N/A	Indefinite, offered on continuous basis	A continuous wellness-based training program to enhance caregiver wellbeing, confidence, on-going self-management, healing, and growth. In addition to regular content, CALM programs provide continuity, practice and connection before, between, and after the completion of other valuable time-limited programs and training for family caregivers around the state. Inspired by the monthly program, Catching Your Breath.	Any
Parkinson Caregiver Education Program^{lxi}	User guided	Online delivery	1 hour	Indefinite, offered on continuous basis	An online training module for caregivers that provides critical care information for direct care workers, family caregivers, home health aides, and others who assist individuals with Parkinson's to ensure better quality care. Topics include disease-specific education, medication management, nutrition, isolation, communication, and managing mental/emotional health challenges.	Parkinson's

Caregiver needs identified in the literature

Many caregivers report unmet needs, despite the existence of various caregiver support programs and methods of program delivery. Research shows that 22 percent of caregivers report at least one unmet need,^{lxii} such as access to community resources, dementia education, emotional support, and respite support. Many of these needs have been addressed in some form by existing programs. Therefore, it may be necessary to consider the shortfalls of common promotional tactics of caregiver programs. The literature review indicated that most caregiver programs are advertised by local health care organizations. This method of recruitment may exclude several groups, such as caregivers who are caring for an individual with a slowly progressing condition that does not require frequent in-person appointments. Individuals working full-time without the ability to attend daytime appointments may often be excluded as well.

Employed family caregivers have reported substantial difficulty in transitioning back into the workforce after caregiving. They also report significant hardships associated with having to manage their paid employment and unpaid caregiving duties. One study estimated that about half of caregivers are employed full- or part-time.^{lxiii} Among employed caregivers, 52 percent indicated that their caregiving had interfered with their employment. These individuals were also more likely to report greater emotional stress related to their caregiving demands. Those with full- or part-time jobs face significant time constraints, which inhibit their ability to engage in certain caregiver support programs and trainings. For these individuals, online or short-duration sessions specific to balancing work and caregiving would be ideal.

One important trend to note among caregivers is the increasing number of long-distance caregivers. It is estimated that over one in ten family caregivers live at least an hour away from the family member in need of care.^{lxiv} There is currently not a widely accepted and utilized definition of “distance caregiver” in the literature. Typically, it is agreed upon that this term is used to refer to someone living at least an hour away from their care recipient, but the activities that count as caregiving from a distance differ. This is still, however, an important subset of the caregiver population that could benefit substantially from greater attention and inclusion in caregiver programs as they are often left out.

Caregiver recruitment and engagement

Individuals may not always identify with the term “caregiver.” When recruiting, it is beneficial to use terms that are respectful and acknowledge care providers’ roles within their family structures. One example of this is, “The balance study: Balancing life and reducing stress for those providing elder care.” This example clearly resonates with a caregiver’s role and challenges without using the term “caregiver.” A systematic review conducted by Whitebird et al (2011)^{lxv} found that using a variety of recruitment techniques, careful attention to language and terminology, and placing a high value on establishing early and ongoing contact with participants improved both program recruitment and retention.

Online recruitment on social media is one technique that can be particularly valuable. One study that compared the effectiveness of Twitter vs. Facebook in recruiting caregivers found that they were able to yield 86 percent of their target sample of 200-400 caregivers on Facebook alone.^{lxvi} This study used an electronic recruitment flyer with pertinent study information on it. Researchers attribute the difference in success between platforms to the volume of users and/or the different audiences on each platform. When recruiting family caregivers via social media, recruiters should keep their tweets/posts active through likes or comments so the tweet/post is towards the top of people’s newsfeeds. They should also list the posting in various areas on a social media platform, such as their own page and public or private support group pages, where appropriate.

One barrier to caregiver recruitment and engagement is difficulty attending in-person programming. Caregivers may lack the resources needed to facilitate attendance, such as transportation and respite care for their loved one.^{lxvii} In addition, caregivers may have trouble finding time in their schedule to participate in these programs, especially if

they are managing other responsibilities such as work or childcare. In an effort to make these programs more accessible, a number of caregiver support programs have been adapted so that they can be delivered online, either synchronously or asynchronously^{lxviii}^{lxix}.

Although interest in online programs has been growing over the past decade, the COVID-19 pandemic has accelerated the adoption of online formats due to restrictions on in-person gatherings. Now that more organizations have developed the infrastructure to be able to offer programs in this format, the ability to reach caregivers who may be hesitant or unable to participate in-person is greater than it has ever been. As COVID-19 restrictions are eased, however, many organizations will have to navigate unprecedented decisions regarding whether and how to sustain this mode of programming, as well as how to integrate this mode with their existing in-person formats. These organizations may benefit from resources that identify barriers, strategies, and best practices for making this transition.

Diversity, equity, and inclusion

About 30 percent of caregivers self-identified as Black, Indigenous, or People of Color (BIPOC) in 2020.^{lxx} This rate is expected to grow over the next several decades. Diverse caregivers can be faced with additional challenges that may increase the stress they experience from caregiver duties. A survey done by the Diverse Elders Coalition in partnership with BRI found that caregivers who perform “cultural tasks” (i.e., interpreting at the doctor’s office for the care recipient) had significantly higher levels of strain and depression compared to those that did not have to perform such tasks.^{lxxi} However, this portion of the caregiver population is often significantly underrepresented in caregiver programs, with program participants typically being white caregivers.

One study found that many caregivers reported a fear of accessing supportive services because of concerns about experiencing discrimination based on their race, sexual orientation, gender identity, or immigration status.^{lxxii} Caregiver support groups that acknowledge the needs of the community and are facilitated by members of the community or individuals who have been trained in cultural competence can help address this. Outreach to diverse communities is also important to ensure that the underutilization isn’t caused by a lack of outreach. The Diverse Elders Coalition (DEC) has put together a toolkit titled, “Caring for those who care - Resources for providers: Meeting the needs of diverse family caregivers toolkit^{lxxiii}” to provide information that can help providers support diverse family caregivers and foster a more welcoming and supportive environment.

Disparities in technology use and access also represent a barrier to equitable access to caregiver programs. Although the proportion of Americans who report that they do not use the internet has declined drastically from 48 percent in 2000 to just 7 percent in 2021, disparities in internet use remain. In particular, adults who are 65 years or older, who reside in rural areas, who have lower incomes, and who have not attended college have lower rates of internet use.^{lxxiv} In order to promote equitable access to programming, some organizations have utilized funds to provide iPads and hotspot services to caregivers.^{lxxv} In addition, some online programs have incorporated an additional session to introduce caregivers to the technology and address any technology-related questions or concerns.^{lxxvi}

Conclusion

Throughout the literature, programs most often provide psychoeducational support; technical, skill-building support; or both. Interventions that combine multiple types of support seem better able to help caregivers. A common example of this is a program that provides both caregiving education as well as opportunities for social support and interaction.

Programs that are adaptable in their delivery method are often able to reach a greater audience as well. Many caregivers do not have the time or resources to attend in-person caregiving sessions, while others are not comfortable using technology and prefer face-to-face interactions. Programs that incorporate multiple delivery

methods, such as in-person and online sessions, or telephone sessions and in-person sessions, may reach broader audiences.

In terms of engagement, the most common way organizations recruit for studies is to post fliers or advertisements in relevant buildings (clinics, hospitals, etc.) that caregivers frequent. This technique, however, has the potential to exclude certain caregiver subgroups. While caregivers are difficult to identify from community settings^{lxxvii}, once identified, these individuals can be enthusiastic about participating. Receiving referrals, often from care providers, is another common mechanism for researchers to identify caregivers to include in their studies.

In the literature (and as seen evidenced in this review), caregiver programs are typically specific to the health condition of the care recipient. This is largely due to the need to provide tailored educational materials to caregivers so they are able to have a functional understanding of that condition. However, apart from the didactic component of caregiver programs, many utilize similar tools to improve caregiver mental health and well-being, such as using mindfulness activities or support networks.

Despite the abundance of caregiver programs that currently exist, there is still a need for programs that are welcoming of diverse audiences, including men, racially and ethnically diverse caregivers, and caregivers who are employed (particularly those who also have children).

Regional estimates of unpaid caregiving in Michigan

Background

There has been much progress in recent years in acknowledging the role that unpaid family and informal caregivers play in the lives of others and in recognizing the unique needs of this population. As a result, many programs have been developed to help support, educate, and assist these caregivers. However, there remains a need to systematically understand the impact, reach, and overall effectiveness of these programs. This information is especially vital in the context of shifting age demographics in Michigan.^{lxviii} Such an understanding can provide an important resource to caregivers, but also to funders who wish to be more strategic in the programs selected for funding. To better understand the prevalence of unpaid family caregivers across the state of Michigan, the CHRT calculated population estimates for different regions of the state.

Methods

Data from CHRT's 2020 Cover Michigan Survey¹, a representative survey of Michiganders, were used to estimate the proportion of adults who are unpaid caregivers in different regions of the state. As part of the survey, respondents were asked whether they regularly provided unpaid assistance or care to another adult; if they answered yes, they were asked whether any of the people that they provided care for were 65 years or older². Respondents who indicated that they provided unpaid care to an adult 65 years or older and lived with someone under the age of 18 were considered sandwich caregivers.

The proportion of adults who were unpaid caregivers for an adult (ages 18+), who were unpaid caregivers for an older adult (ages 65+), and who were sandwich caregivers were calculated for each region. The proportion of older adults (ages 65+) who were unpaid caregivers was also calculated for each region.

Estimates of the number of adults (ages 18+) and older adults (ages 65+) in each region were calculated using data from the the 5-year American Community Survey (ACS) released in 2019. To determine the number of caregivers per region, the proportions of unpaid caregivers identified from the Cover Michigan Survey were applied to these ACS population estimates.

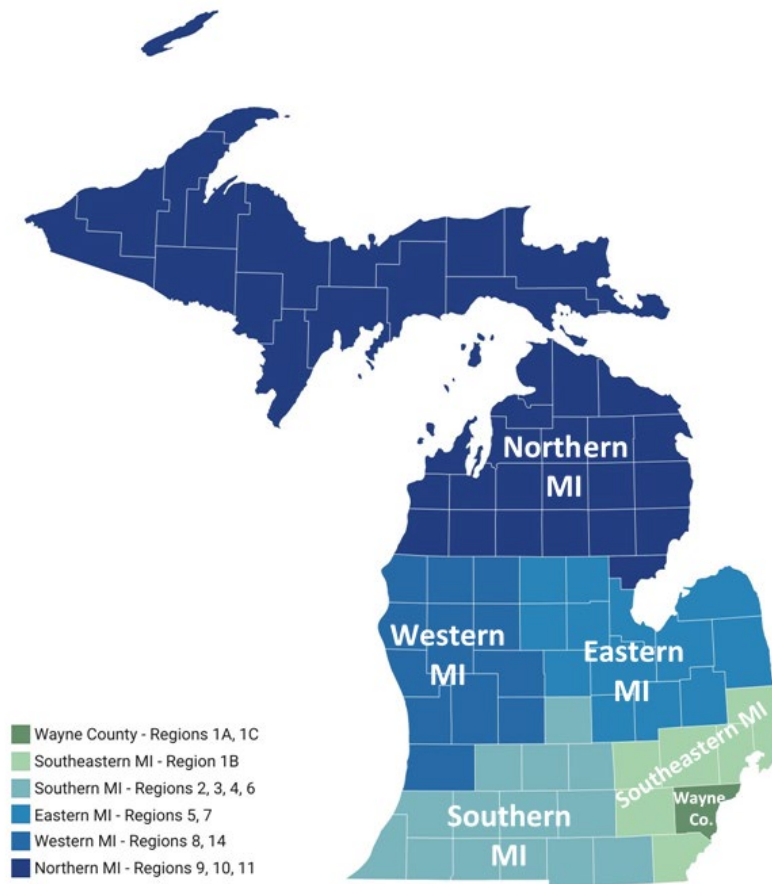
The Area Agencies on Aging (AAA) regions were categorized into the following groups (displayed in Figure 1): Regions 1A & 1C (Wayne County); Region 1B (Southeastern MI); Regions 2, 3A, 3B, 3C, 4, & 6 (Southern MI); Regions 5 & 7 (Eastern MI); Regions 8 & 14 (Western MI); and Regions 9, 10, & 11 (Northern MI). This was done to ensure that there were enough respondents in each regional group to obtain reliable estimates.

¹ CHRT's Cover Michigan Survey is comprised of a series of survey questions added to the Michigan State University Institute for Public Policy and Social Research (IPPSR) quarterly State of the State Survey (SOSS). SOSS is a public opinion survey that includes a stratified random sample of Michigan adults aged 18 years and older. Cover Michigan 2020 was fielded online in February 2020 and included a sample of 1,000 Michigan adults. The sampling frame was matched to gender, age, race and education and stratified by the 2016 American Community Survey (ACS) one-year sample. Selection was done within strata by weighted sampling with replacements. Matched cases were weighted to the frame with a propensity score. The weights were post-stratified on 2016 Presidential vote choice, gender, age, race, and education, to produce the final weight.

² In particular, respondents were asked "Often times, people may provide care or assistance for other adults in their lives. This can include things like running errands, helping out financially, taking them to appointments or helping around the house. Typically, these activities are unpaid, meaning a person does not receive any compensation for doing these things. Do you provide any unpaid assistance or care on a regular basis to another adult?" and "Are any of the people you provide unpaid care for 65 years or older?"

Figure 1

AAA region grouping

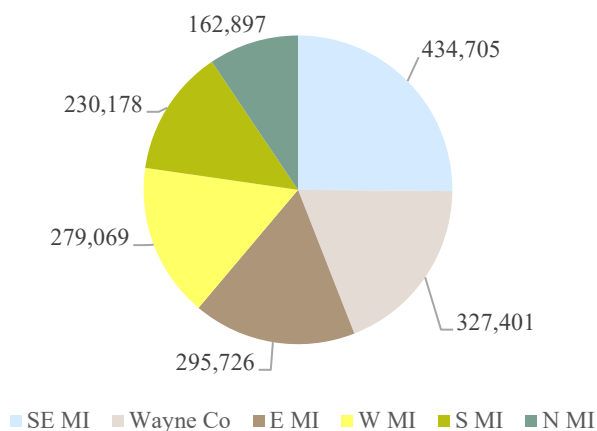


Caregiver estimates by region

Overall, an estimated 1,729,975 adults in Michigan provide unpaid care to another adult. The largest share of these caregivers are from Southeast Michigan (25 percent), followed by Wayne County (19 percent), and Eastern Michigan (17 percent) (see Figure 2).

Figure 2.**Proportion of unpaid caregivers by region.**

An estimated 1,729,975 adults in Michigan provide unpaid care to another adult.



Regional comparisons of caregiver prevalence

Unpaid caregivers for an adult

Approximately 23 percent of adult Michiganders provide unpaid care to another adult (see Table 4). The percentage of unpaid caregivers within each region varies slightly, with Eastern Michigan having the highest percentage and Southeast and Southern Michigan having the lowest percentages. Compared to adults overall, a greater share of older adults report providing unpaid care (28 percent). The prevalence of older adult caregiving was highest among older adults in Wayne County and lowest among older adults in Western Michigan. However, none of these regional differences are statistically significant, suggesting that the prevalence of unpaid caregivers is fairly consistent across the state. These slight regional differences in caregiving for all adult caregivers (Figure 3) and for older caregivers (Figure 4) are displayed as maps below.

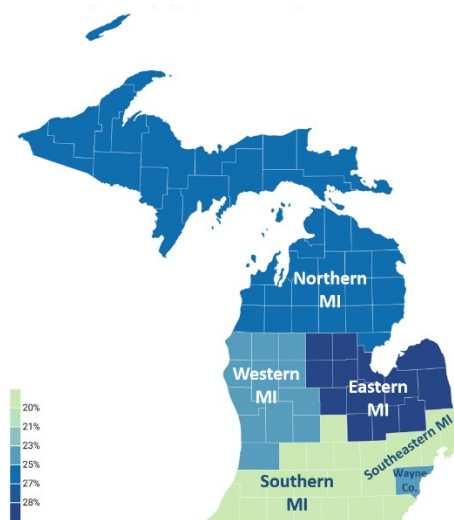
Table 4.

Regional estimates of the number and percentage of adults and older Adults who provide unpaid care to another adult

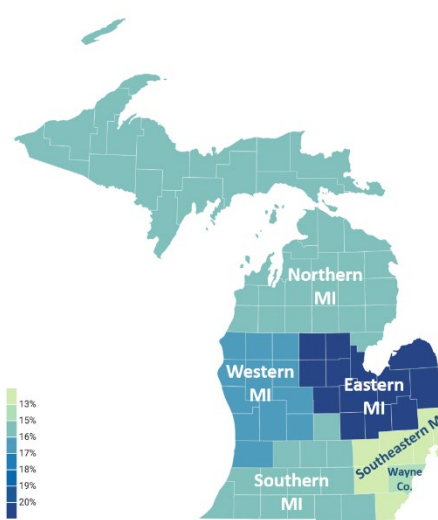
		Wayne	SE MI	S MI	E MI	W MI	N MI	
		Regions 1A & 1C	Region 1B	Regions 2, 3, 4, & 6	Regions 5 & 7	Regions 8 & 14	Regions 9, 10, & 11	State-wide
All Adults (ages 18+)	#	327,401	434,705	230,178	295,726	279,069	162,897	1,729,975
	%	24%	18%	18%	30%	24%	25%	23%
Older Adults (ages 65+)	#	95,758	135,372	61,537	68,688	49,257	56,922	467,534
	%	36%	28%	23%	31%	21%	30%	28%

Figure 3.

Percentage of each region's adult (18+) population that are caregivers

**Figure 4.**

Percentage of each region's older adult (65+) population that are caregivers



Unpaid caregivers for an older adult

When specifically considering those who provide unpaid care to an older adult, a similar pattern emerges (see Table 5). Compared to the overall population, older adults are more likely to provide unpaid care to someone ages 65 and older. The percentage of older adults who provide care to another older adult is highest in Wayne County and lowest in Western Michigan. Again, none of these regional variations are statistically significant, suggesting that the percentage of Michiganders who provide care to an older adult does not vary widely across the state (see Figures 5 and 6).

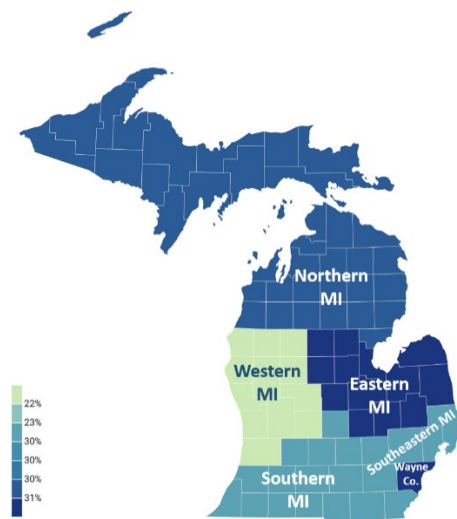
Table 5.

Regional estimates of the number and percentage of adults and older adults who provide unpaid care to an older adult

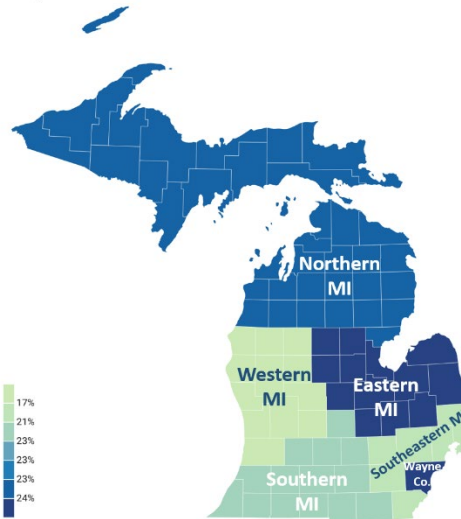
		Wayne	SE MI	S MI	E MI	W MI	N MI	
		Regions 1A & 1C	Region 1B	Regions 2, 3, 4, & 6	Regions 5 & 7	Regions 8 & 14	Regions 9, 10, & 11	State-wide
All Adults (ages 18+)	#	189,215	290,037	191,316	206,683	183,570	101,734	1,162,556
	%	14%	12%	15%	21%	16%	15%	15%
Older Adults (ages 65+)	#	95,758	88,131	56,109	52,774	31,648	42,566	366,987
	%	36%	18%	21%	24%	14%	23%	21%

Figure 5.

Percentage of each region's adult (18+) pop. that are caregivers for older adults

**Figure 6.**

Percentage of each region's older adult (65+) pop. that are caregivers for other older adults



Sandwich caregivers

Approximately 3 percent of adults statewide are sandwich caregivers, providing unpaid care to an older adult while also living with someone under the age of 18. There is evidence of regional variation in the percentage of adults who are sandwich caregivers. In particular, adults in Southeastern MI are less likely to be sandwich caregivers than adults in Wayne County, Southern Michigan, and Western Michigan (see Table 6).

Table 6.

Regional estimates of the number and percentage of adults who are sandwich caregivers

		Wayne	SE MI	S MI	E MI	W MI	N MI	
		Regions 1A & 1C	Region 1B	Regions 2, 3, 4, & 6	Regions 5 & 7	Regions 8 & 14	Regions 9, 10, & 11	State- wide
All Adults (ages 18+)	#	52,079	4,261	57,246	26,978	51,347	22,997	214,908
	%	4%	<1%	5%	3%	4%	3%	3%

Conclusions

Caregivers are frequently described as the “backbone” of the healthcare system in the United States^{lxxix}. Michigan is no exception, with an estimated 1,729,975 adults providing unpaid care to an adult (approximately 23 percent of the population). Although the largest shares of Michigan’s caregivers are concentrated in more populated areas of the state (i.e. Southeast Michigan and Wayne County), overall the percentage of adults who are caregivers is fairly consistent across the state. These estimates are helpful for establishing a baseline by which to assess the reach and engagement of programs that serve unpaid caregivers in different areas of the state.

Assessing the reach of caregiver programs in Michigan

Background

A review of the literature suggests that many caregivers report unmet needs, despite the existence of various caregiver support programs and methods of program delivery. In order to better understand who is engaging in caregiver support programs across Michigan, CHRT turned to public data sets due to nonstandard evaluation and reporting of these types of programs. This work seeks to inform efforts to facilitate caregiver recruitment and engagement.

Methods

Data from CHRT's 2020 Cover Michigan Survey³, a representative survey of Michiganders, were used to estimate the demographic characteristics of adults who are unpaid caregivers for an older adult in Michigan. As part of the survey, respondents were asked whether they regularly provided unpaid assistance or care to another adult; if they answered yes, they were asked whether any of the people that they provided care for were 65 years or older⁴.

To estimate the demographic characteristics of caregivers for older adults who receive supportive services, data from the National Aging Program Information Systems (NAPIS) State Program Reports are used. This dataset includes information collected from State and Area Agencies on Aging (AAA) regarding the clients they serve through Older Americans Act (OAA) Title III, VI (Chapters 3 & 4 grants), and VII programs. For the purposes of this report, 2019 data on the demographic characteristics of the caregivers served in Michigan are analyzed.

To estimate the reach of caregiver services and programs in Michigan, Cover Michigan Survey estimates of the demographic characteristics of those who provide unpaid care to older adults in Michigan are compared to NAPIS State Program Report data on the demographic characteristics of caregivers served through OAA supportive service programs.⁵

Overall reach of caregiver programs

Estimates suggest that 1,162,556 adults in Michigan provide care to an older adult. In 2019, NAPIS State Program Report data suggest that 5,419 caregivers received support through the State and Area Agencies on Aging (AAA). Although not all caregiver programs and services available in Michigan are captured in the State Program Report

³ CHRT's Cover Michigan Survey is comprised of a series of survey questions added to the Michigan State University Institute for Public Policy and Social Research (IPPSR) quarterly State of the State Survey (SOSS). SOSS is a public opinion survey that includes a stratified random sample of Michigan adults aged 18 years and older. Cover Michigan 2020 was fielded online in February 2020 and included a sample of 1,000 Michigan adults. The sampling frame was matched to gender, age, race and education and stratified by the 2016 American Community Survey (ACS) one-year sample. Selection was done within strata by weighted sampling with replacements. Matched cases were weighted to the frame with a propensity score. The weights were post-stratified on 2016 Presidential vote choice, gender, age, race, and education, to produce the final weight.

⁴ In particular, respondents were asked "Often times, people may provide care or assistance for other adults in their lives. This can include things like running errands, helping out financially, taking them to appointments or helping around the house. Typically, these activities are unpaid, meaning a person does not receive any compensation for doing these things. Do you provide any unpaid assistance or care on a regular basis to another adult?" and "Are any of the people you provide unpaid care for 65 years or older?"

⁵ There are some limitations to this comparison. First, NAPIS State Program Report data do not include information on caregivers served through non-OAA services and programs; therefore, these analyses do not capture the full reach of caregiver programs and services throughout the state. Second, in the Cover Michigan Survey, the care recipients in question are older adults ages 65 and older, whereas, given the nature of who is eligible to receive OAA benefits, the care recipients in the NAPIS State Program Report could be 60 years and older. Despite these limitations, we feel that this comparison gives a reasonable approximation of the reach of caregiver services and programs in Michigan.

data, these estimates suggest that a considerable proportion of caregivers for older adults are not being reached by current caregiver programs and services.

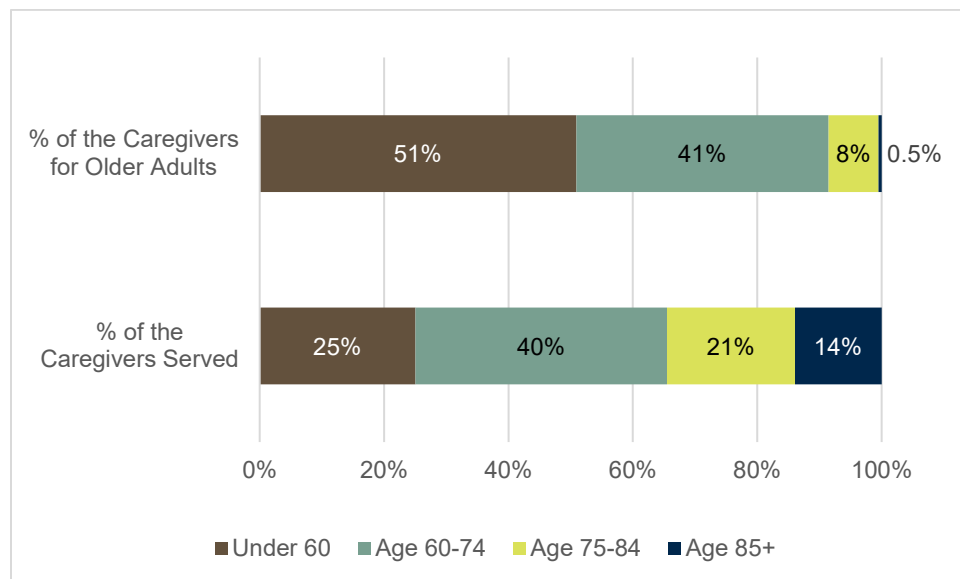
Assessing reach by caregiver demographics

Age

Estimates suggest that caregivers under the age of 60 are less likely to participate in OAA services and programs. Although these younger caregivers make up approximately half of the adults caring for an older adult in Michigan, they represent only 25 percent of those who participated in OAA caregiver programs. In contrast, while 9 percent of those who provide unpaid care to an older adult are ages 75 and older, 35 percent of those who utilized OAA caregiver services were ages 75 and older (Figure 7).

Figure 7.

Caregivers under the age of 60 are underrepresented in caregiver supportive service programs



Data Sources: 2020 Cover Michigan Survey & 2019 NAPIS State Program Report

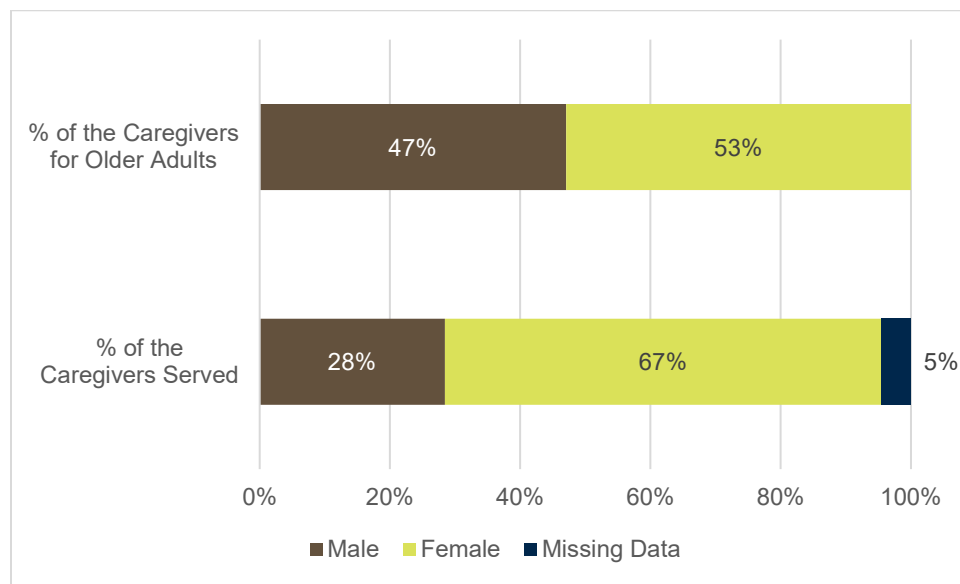
Note: Due to rounding, percentages may not total to 100%.

Gender

Of those who care for older adults in Michigan, approximately 47 percent are estimated to be men and 53 percent are estimated to be women. When it comes to participation in OAA caregiver support services and programs, however, male caregivers are underrepresented. Approximately seven out of 10 caregivers who utilized these caregiver services and supports were women (Figure 8).

Figure 8

Male caregivers are disproportionately less likely to participate in caregiver service support programs than female caregivers.



Data Sources: 2020 Cover Michigan Survey & 2019 NAPIS State Program Report

Race and ethnicity

Although OAA services and supports are generally open to individuals ages 60+ and their caregivers, the program prioritizes offering assistance to those with the greatest social and economic needs—including low-income and racial and ethnic minority populations.^{xxx} As might be expected based on this prioritization, preliminary analyses suggest that while white caregivers represent 86 percent of the caregivers in Michigan, they represent 82 percent of those served by OAA services and supports. In comparison, although Black caregivers are estimated to represent 9 percent of the caregivers in Michigan, they represent 17 percent of those served by OAA services and supports.⁶

When it comes to ethnicity, preliminary analyses suggest that while Hispanic/Latinx caregivers are estimated to represent 2 percent of the caregivers in Michigan, they represent only 1 percent of the caregivers served by OAA services and supports.⁸ This percentage of the caregivers served represents less than one might expect given that this population represents a priority group for OAA services.

It is important to note that in the NAPIS State Programs Report data, 11 percent of the caregivers were missing information on race, and 14 percent were missing information on ethnicity. Consequently, these findings should be interpreted with caution.

Relationship to the care recipient

⁶ Those with missing data on race were not included in the calculation of these percentages.

National estimates from the National Study of Caregiving suggest that, of those who provide unpaid care to an older adult, approximately 49 percent care for a spouse and 36 percent care for a parent.^{lxxxi} However, according to NAPIS State Program Report data, only 5 percent of caregivers served by OAA services and supports were providing care to a parent, while 63 percent were providing care to a spouse. These NAPIS State Program Report estimates should be interpreted with caution, as 59 percent of caregivers were missing data on their relationship to the care recipient. Nonetheless these preliminary analyses, combined with the earlier finding those under the age of 60 are underrepresented in OAA services and supports, suggest that adult children providing care to a parent are less likely to access these services and programs.

Conclusions

Overall, these findings suggest that a considerable proportion of caregivers for older adults are not being reached by current caregiver programs and services in Michigan. Younger caregivers, male caregivers, and Hispanic caregivers in particular are underrepresented in Older Americans Act caregiver services and programs. Future work is needed to understand why these populations are less likely to access these services, as well as to identify potential strategies for reaching these segments of the caregiver population.

In addition, in the NAPIS State Programs Report data, 11 percent of caregivers were missing information on race and 14 percent were missing information on ethnicity. With that level of missing data, it is more difficult to assess whether Older Americans Act services and supports are successfully reaching racial and ethnic minority populations, which represent key priority populations for OAA funds. Future work is needed to identify any barriers to reporting racial and ethnic data, as well as to determine strategies to encourage complete reporting of this information.

Michigan-based scan of programs

Background

In order to better understand the implementation of caregiver support programs CHRT initiated data collection in winter and spring 2021 with Michigan-based organizations. Data collection focused on descriptions of program components, perceived strengths and challenges of the programs, staff capacity and ability to meet demand, barriers to engaging caregivers in programs, and the impact of COVID-19 on caregivers and programming.

Methods

Interviews with Area Agencies on Aging (AAAs)

Key informant interviews with Michigan's sixteen AAAs occurred in spring 2021. Recruitment of relevant staff targeted individuals involved in supporting caregivers through programs and services. One group interview was conducted for each AAA region. Contact was initially made through Area Agencies on Aging Association of Michigan (4AM) via an email sent to the AAA directors with follow-up emails sent directly by the CHRT team. Respondents were asked to provide a list of their programs supporting unpaid and informal caregivers in advance of the interview to help focus the discussion. Interview questions addressed topics such as:

- Components of the program(s) and experiences implementing the program(s)
- Perceived strengths and challenges of the program(s)
- Impact of COVID-19 on program implementation and on caregivers
- Staffing
- Ability to meet caregiver needs and demand
- Funding and sustainability
- Biggest challenges currently facing caregivers

See Appendix A for the full interview guide. In addition, after the interviews, AAAs were asked to share any previously developed reports that could provide the research team with a greater understanding of the population served, class size and frequency, and key process and outcome measures being tracked.

Surveys with community-based organizations and hospitals

In addition to interviews, online surveys were administered to community-based organizations and hospitals in winter and spring 2021 through the Qualtrics survey platform. Community-based organizations were identified using online search tools for informal and unpaid caregiver support programs in Michigan along with MDHHS resource webpages. Twenty-eight organizations responded to the survey, and twenty of the organizations indicated that they offered caregiving programs. The sample included many county councils and commissions on aging as well as universities. The CHRT team directly contacted individuals associated with these organizations via email. Outreach to hospitals occurred through the Michigan Health and Hospital Association (MHA). The surveys focused on similar topics as the interviews, such as: types of programs being implemented, populations served, methods of delivery, demand vs. staff capacity, as well as funding and sustainability (with hospitals receiving a more condensed version of the survey). Overall, twenty-four representatives from seventeen hospitals responded to the survey. See Appendix B and C for the full surveys.

Core evidence-based programs in Michigan

Table 7 highlights the core evidence-based programs being utilized by AAAs around the state (full descriptions of the programs are available in the literature section Tables 1-3). The table provides a breakdown of the reported strengths and challenges associated with each of the core programs as well as the AAA regions where they exist. Overall, Creating Confident Caregivers (CCC) had the most widespread use across the state. The program, which launched under MDHHS in 2008, is based upon Savvy Caregiver. It's a six-week program for family caregivers of persons with dementia. It has a strong evidence base and is designed to provide knowledge, skills, and information to improve caregiving for both the caregiver and the person with dementia. AAAs were largely positive in discussing CCC and reported positive feedback from caregivers regarding the peer learning, self-care, and empowerment aspects of the program. The intensity of the program (including the amount of information caregivers are expected to receive and time commitment for participants) was cited by multiple AAAs as a challenge. Additionally, the program has strict requirements in how it is delivered (including class size and delivery method) that created difficulties for some respondents. Several AAAs indicated their preference for the flexibility permitted by the traditional Savvy Caregiver model. For example, one AAA stated their appreciation that the Savvy Caregiver program could be delivered inside a caregiver's home in a one-on-one scenario rather than having to adhere to a larger class size requirement to maintain fidelity.

[Reflecting on delivering Savvy Caregiver to an individual in their home]: In some ways, because it's one on one...it had a much greater impact, so we used a lot of those [informal methods] more...through the coaching we do with our community health workers. I think one of the gaps that we currently have...there's all sorts of caregiver programs, but nearly all of them are based on group settings on prescribed outcomes...and are not really as person-centered or allow for ongoing support. So I think TCARE has some of that in it, where they're addressing specific strategies, behaviors, those type of things, but are using our community health workers [to coach individuals].

During the early stages of the pandemic, CCC was only approved for in-person delivery and therefore the program was halted statewide. Only recently was the program approved for online delivery. MDHHS also created a streamlined version of the program earlier in the pandemic specifically designed for online delivery called Developing Dementia Dexterity, which can be used to educate both informal and formal caregivers.

Powerful Tools for Caregivers was the second most common program discussed during the interviews with AAAs. Respondents largely appreciated that the program is not disease-specific and therefore open to all types of caregivers. Again, the focus on self-care and empowerment were viewed as strengths of the program. Similarly, restrictions on delivery (e.g. in-person and class size requirements) to ensure fidelity were viewed as a challenge for some. Once the program had been approved for online delivery, several AAAs noted technological barriers for recruitment and accessing the virtual programs.

Many AAAs made adaptations to programs and services, so that they could continue to support caregivers throughout the COVID-19 pandemic. Many programs that were previously delivered in-person or even in a client's home were delivered through virtual platforms, such as Zoom and Facebook Live. Benjamin Rose Institute (BRI) Care Consultation, TCARE and Trualta all represent programs that can be delivered remotely through online educational modules, emails, or telephone engagement. They support caregivers generally (not condition-specific). Several AAAs stated that TCARE, in particular, is very labor intensive for staff. Several AAAs indicated that Trualta, which is a newer program, shows promise. BRI Care Consultation was viewed as a very strong program for rural areas, where transportation barriers create challenges for in-person programs.

Table 7.

Core evidence-based programs in Michigan

Program Name	Strengths	Challenges	Areas implementing
BRI Care Consultation	<p>Open to all caregivers (not condition specific)</p> <p>Flexible</p> <p>Has caregiver assessment, but it is more informal and allows the caregiver to lead the conversation</p> <p>Evidence-based but can tailor to suit their needs. Telephone and email based, so convenient for caregivers—good for area that is rural and spread out or where transportation is more of an issue</p>	Learning how to balance staff capacity-case load	11
Creating Confident Caregivers	<p>Evidence base</p> <p>Provides great information for those in the thick of it with dementia helping them better understand disease progression</p> <p>Connects caregivers with their peers. Validates caregiver experiences when interact with other caregivers</p> <p>Very positively received by caregivers, great feedback</p> <p>Provides resources and community supports</p> <p>Addresses caregiver self-care</p> <p>Emphasizes benefit of creating a plan as an empowering action.</p> <p>Not a scripted program so you can tailor presentation to what</p>	<p>Intense</p> <p>Technical program, there is a lot of material</p> <p>Some caregivers do not embrace program because would like a broad program, not dementia specific</p> <p>Barriers to in-person trainings</p> <p>Class size requirement</p> <p>Previous requirement to be in-person prior to pandemic</p> <p>Logistical issues such as time commitment, scheduling, transportation, location, need for respite care</p>	1A, 2, 3A, 3B, 5, 6, 9, 10, 11

	<p>you are comfortable with</p> <p>Creates an environment in which people feel comfortable sharing</p>	<p>Recruitment for some areas</p> <p>Facilitators must complete a minimum number of classes a year to maintain certification and compliance</p> <p>Staff turnover-staffing issues</p> <p>Virtual format not approved by state at the beginning of pandemic</p> <p>Challenges with new virtual format</p> <p>Figuring out how to promote or market.</p> <p>Sometimes hard to get caregivers to share experiences on the virtual platform</p> <p>Lack of high-speed internet access for some</p> <p>Time commitment</p> <p>Requirement for two staff facilitators</p> <p>Strict fidelity to the model</p>	
<p>Developing Dementia Dexterity</p>	<p>Focus specifically on caregivers</p> <p>Focus specifically on dementia</p> <p>Virtual offerings</p> <p>Developed by MDHHS Office of Services to the Aging</p>	<p>Unsure how to market well for virtual program. Can be difficult to recruit</p> <p>Sometimes hard to get caregivers to share experiences on the virtual platform</p>	<p>1A, 2, 3A, 5</p>

	<p>(OSA) to bring initial dementia education programs online due to COVID</p> <p>Open to formal and informal caregivers</p> <p>Shorter sessions</p>	<p>Missing some demographics who lack internet access.</p> <p>Technological challenges for some caregivers due to online delivery</p> <p>Not as detailed as CCC</p>	
Powerful Tools for Caregivers	<p>Open to all caregivers, not disease-specific</p> <p>For one site, this was viewed as a strength for recruitment pre-COVID but they believe it might have hindered recruitment during the pandemic</p> <p>Popular with caregivers</p> <p>Empower the caregiver with skills to take care of themselves</p> <p>Positive feedback from caregivers because it gives them support</p> <p>Focus on self-care and creating an action plan is helpful</p>	<p>Recruitment and retention challenges for virtual trainings, which started with the pandemic</p> <p>Technological barriers to virtual trainings including equipment and internet access issues for some</p> <p>Time commitment</p> <p>Difficult getting enough participants to meet fidelity</p>	1A, 1B, 3A, 5, 6, 9, 11, 14
Savvy Caregiver	<p>Evidence base</p> <p>Evaluation data indicates participants value the information and feel more empowered</p> <p>Successful referrals</p> <p>Flexibility</p> <p>More flexible than Creating Confident Caregivers</p> <p>Able to be more person-centered or have more flexibility in how it's offered (e.g. allows you to implement at someone's house)</p>	<p>Time commitment</p> <p>Transportation, scheduling, or other logistical barriers for in-person offering</p> <p>Virtual training has technological barriers for some</p>	2, 3B, 6, 14

TCARE	<p>Evidence base</p> <p>Assessment tool helps caregivers to see where they are on a scale and where their stressors are</p> <p>Online delivery of education</p> <p>Specific focus on the caregiver</p> <p>Could still make an impact on individuals if they cannot complete a full program</p> <p>People stay engaged after 3 months</p>	<p>A lot of time is devoted to assessment, and some caregivers were frustrated by that</p> <p>Very labor intensive and care managers are already very busy. It's a balancing act with trying to balance the cases and other duties</p> <p>New model is believed to be more user friendly</p> <p>Cost</p>	1A, 1C, 3B
Trualta*	<p>Great training tool</p> <p>Covers many different topics with valuable information</p> <p>Most courses short—as short as 5 minutes, good for busy caregivers</p> <p>Flexible—allows for the caregiver to do on their own time.</p> <p>Connects to Area Agency on Aging</p> <p>Staff can suggest different trainings based on conversations with caregivers</p> <p>Can promote other community resources on the platform, post upcoming workshops, flyers on vaccines, etc.</p> <p>Can run reports on what caregivers are doing</p> <p>Multimodal</p> <p>Most people will view the content the way it's originally set</p>	<p>It takes a lot of administrative time to make sure users feel confident enough to get through activities, lots of follow-up to keep them engaged</p> <p>Someone who is not as comfortable may need guidance to find information on the platform</p> <p>Not a lot of people know about it, only a few AAAs in the state have it</p> <p>Internet access limitations</p>	1B, 2, 14

	up Also can have the content mailed to someone if someone isn't comfortable accessing it electronically		
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*Note: Trualta is classified as a “evidence-informed” program

We know there's a great need out there, but also in our area it's just the whole accessibility issue...there's a good chunk of [the area] that doesn't have [broadband] internet access....so you can only do so much virtually.

When describing the available resources for caregivers in their areas, many AAAs highlighted support groups, kinship caregiving programs, counseling, MI Choice Waiver program⁷, and in-home supports. While these programs and services are incredibly valuable, we categorized them as outside of the scope of our work to document unpaid and informal family caregiver support programs. In addition, respondents mentioned various dementia education programs over the course of the interviews (including: Confident Dementia Caregiving, Practical Approaches to Dementia, Dementia Friends, Best Friends Approach to Dementia Care, and Dementia Live), but we have not detailed those programs here, due to the previous work done by the Best Practice Caregiving initiative to catalog evidence-based caregiving programs related to dementia. Three AAAs stated that they use Personal Action Toward Health (PATH) to support caregivers, but given that the program is not tailored specifically to caregivers, we did not include this as a core caregiver program.

AAAs also regularly provide respite care for short-term caregiver relief. When programs are offered in-person, there is often a need for respite so the caregiver is able to participate. During the pandemic, inability to offer respite safely and direct care worker shortages created barriers to participation for many caregivers. Programs like adult day cares also closed which has left caregivers without support during the pandemic. Respite Education and Support Tools (REST) is a program that two AAAs had used previously that helps to train friends and family members to be trained to offer respite care. While the program was viewed as well-designed and organized, one AAA stated that they struggled to find an audience and has discontinued its use.

Caregivers of someone living with dementia...if they're supervising that person may be wandering through the homes through the room that the person is trying to participate from. It's difficult, I think, to commit sometimes to a six-week class, at the same time you're supervising someone who is unpredictable. When the class meets in person, we can offer respite care that the person is not anywhere near...the classes. So you don't have that element...which is an issue for a caregiver.

Figure 9 presents the major barriers to engaging caregivers with programs referenced by AAAs. Staffing and logistics related to program implementation, including location of training, and time of day programs were offered were the most common challenges cited. As programs moved to more online delivery in the pandemic, access to the internet and devices, as well as technological understanding became an increasing limit to engagement of caregivers. Other frequent themes included the time commitment and intensity of programs for participants and factors related to fidelity including class size and mode of delivery. One respondent described the challenges associated implementing evidence based programs in their area due to requirements related to fidelity.

I'd say they're under-utilized and... that many of the programs that we have available aren't the right fit. We keep trying to make Creating Confident Caregivers and Savvy Caregiver fit. I think we need some other tools that use the some of the same principles...and puts it in a format that will be more attractive to different caregivers. Think about the generational differences, getting working adults to commit to eight weeks in an evening. Particularly if they happen to be a millennial or...a sandwich [caregiver] and saying, 'But we need you to attend all eight weeks or we're not going to give you this valuable information.' That's how Creating Confident Caregivers

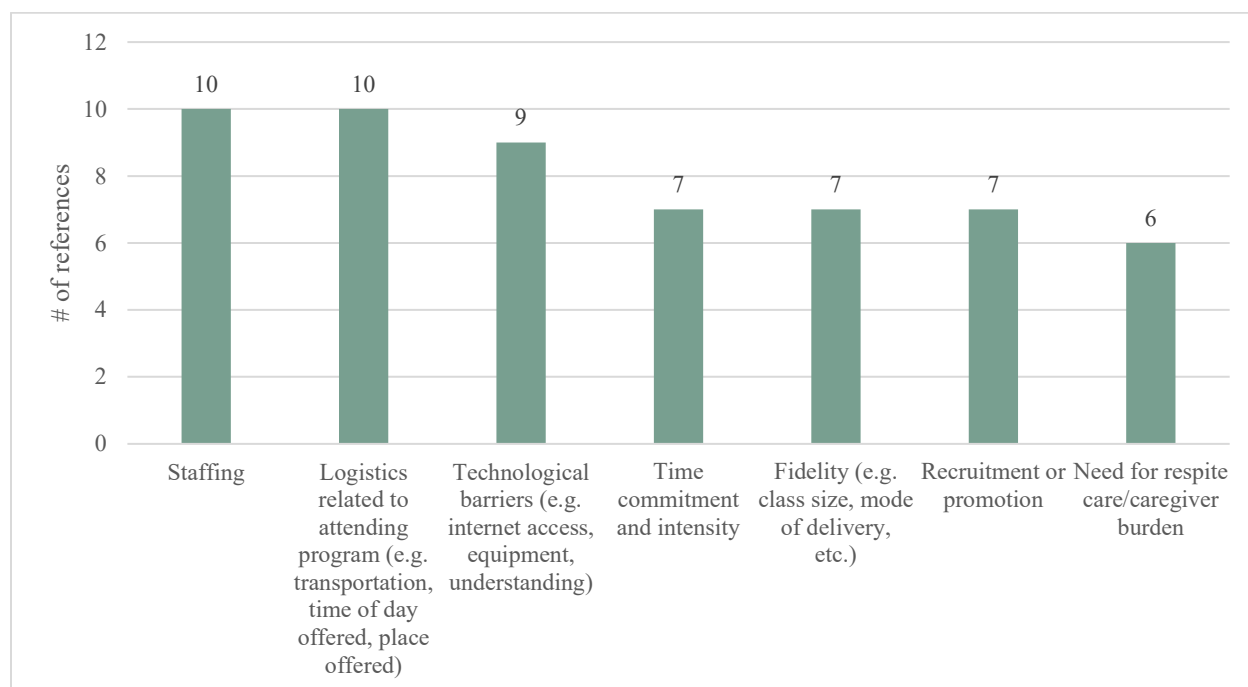
⁷ Provides Medicaid-covered long term care services and supports in a home or residential setting for individuals who meet the medical/functional criteria for nursing facility level of care.

and Savvy feels to me. 'Unless you give us your soul we're not going to share this information.' So I don't think that works, we need something else, whether it's a workshop format, whether it's...virtual.

Challenges finding effective recruitment and marketing strategies is another area AAAs saw as a barrier to their program participation, especially as more traditional in-person promotional activities were limited with COVID-19 and a greater emphasis was needed with online advertising. Lastly, the need for respite care and the barriers of caregiving responsibilities were also commonly viewed as limits to participation.

Figure 9.

Barriers to engaging caregivers in programs



All of these challenges identified through the AAA interviews were also identified as challenges in the hospital and organization surveys. When asked what was needed to expand their programs to meet the demands and needs of family and informal caregivers, increased staffing was the most common response in the organizational survey, and was among the most commonly mentioned responses in the hospital survey. The need for better recruitment and promotion was also a major theme in both surveys. In the hospital survey, increased awareness was the most frequently identified barrier to expanding the programs to meet the demands and needs of family caregivers. For example, one respondent mentioned the need for “additional PR/marketing support to help spread awareness of our services and program to a broader audience.” Another cited the need for “continuous outreach. Members have spouses who expire and new members need to join in.” In the organizational survey, the perception that caregivers had limited awareness of the available caregiver services and supports was also common. When asked how they would rate caregiver awareness of their program and service offerings, only one organization indicated that caregivers were highly aware of their caregiver program. Organizations described nearly half of the programs (47 percent) as having only a low level of awareness from caregivers.

One identified barrier to expanding caregiver programs that was unique to the hospital survey was the need to demonstrate a return on investment. One respondent mentioned that it would be helpful if there was a “data analytics team to help capture and support services to show ROI.”

Capacity vs demand

Getting a sense of class capacity during the COVID-19 era represents a challenge given the shift in work away from in-person programs as a result of pandemic-related restrictions. For many evidence-based programs, implementation of the programs was halted until the online delivery was approved by program developers. With virtual classes, organizations do not have to be as restrictive with class sizes (unless dictated by an evidence-based protocol). When the virtual programs began implementation, many AAA’s opened their trainings to caregivers across the state, under the coordination of 4AM.

We’ve been able to [delivery program] virtually and have participants from all over the state...I think that’s an effort that started a few months ago...The different regions that are offering programs have decided...they will offer to anyone in the state and so that gave more opportunity, more choice for the participants in terms of times available. In the fall, we were just trying to get our local people signed up, but we were having trouble promoting where we used to promote through senior centers, people just weren’t getting out in the community. Since at least probably after the first of the year we had more collaboration between different communities.

Of the organizations surveyed, none indicated that a caregiver program was over capacity; half of the programs offered were described as at capacity, while the other half were described as under capacity. Similarly, prior to the pandemic, none of the AAAs described their programs as over capacity, although a small number of sites did indicate the existence of waitlists for a specific program or service. This is probably due in part to restrictions on class size for fidelity, wanting to keep the size of the class manageable for staff to ensure quality of engagement, as well as an issue of lack of demand.

At capacity, because meeting face to face, you know you want to try to keep it within a certain realm where people are able to engage and it’s not...so large. You know that...everybody doesn’t have an opportunity to speak and participate in...because they are very participatory.

I think what we need to be doing more of is reaching out to caregivers. We’ve been hesitant to do that because we have a waitlist...I think it’s time we do try to reach out to more caregivers who are out there and who absolutely are not connected and don’t know what’s available and are feeling overwhelmed...I think we can meet the need, but I think we probably will discover that there are different kinds of needs out there too.

Generally, the AAAs reported a mixture of programs operating at capacity or somewhat under capacity. One site stated that they typically try to fill classes to capacity and may postpone implementation until the class is full. AAAs largely indicated that they are able to sufficiently meet the demand of caregivers in their area with their current resources. Although there may be some waitlists for programs or services, current funding and staffing seems to adequately meet the needs of those caregivers seeking support. In fact, many AAAs stated that they were reaching more caregivers now than they were before the pandemic.

I think some of our referrals increased because there weren't paid caregivers, weren't in the home, people weren't going to adult daycare [due to COVID-19] and [caregivers] were realizing just how intense this is [without those additional supports]

Although some regions have seen an increase in demand throughout COVID-19, the pandemic has also negatively impacted the demand in some regions for specific programs, with some AAAs noting that many programs which were traditionally advertised and requested through senior centers and delivered in person were not frequently requested by caregivers.

A few sites indicated that staffing challenges created some limitations regarding capacity, specifically, but most AAAs seemed to feel that there was room for some growth in demand for programs under current resources. As noted earlier, however, lack of staff, including direct care workers and respite services, was a frequently cited barrier to engaging caregivers in programs.

I would love a more stable workforce... Sometimes it's just hard to keep people and it's not like you get into human services to make big bucks. Everybody knows that you come to human services to assist and support and help and connect people to resources that they're looking for... I think people look at it sometimes as a step ladder and a career builder, so they'll stay for a couple years and then out.

The biggest thing right now is even if we had all the money in the world there's nobody to pay to provide these services. Even if we get people onto our caseload... there's just not the workers out there and that leads to other issues like... fall-related deaths. I think we're just seeing a domino effect of not being able to have services in the home, and people... have to seek other alternatives to stay safe...

Some sites reported challenges recruiting and retaining participants in programs prior to the pandemic, stating that engaging clients and getting them to complete has been a longstanding challenge.

Sometimes getting the completers is what can be a challenge, because you have to commit to a certain amount of weeks... that's always been a little challenging with the courses. I think we... [are] very diligent to try to stay in touch with people and say 'Hey, what's the barrier?' and try to work through those challenges. We have completers... it's just a struggle to keep people... they're having burden and... it's hard to commit. So that's why the virtual trainings [could be valuable], though, because you sit right in front of your computer from your house... so it will be interesting to see how it goes into the future.

A consistent theme, which resonated across most of our interviews, was that there are a substantial number of caregivers who do not recognize that they are caregivers and are unaware of or reluctant to engage in supports.

Even when we do our educational programming, a lot of times individuals don't identify as a caregiver. You know, that's just part of life: they raise children and they're married and taking care of a spouse is just part of life that doesn't change who they are, so they don't always identify as a caregiver.

I think the big issue right now is we're still touching a real small number of caregivers that need assistance. Until everybody's aware that this is available, and marketing is a part of that, we're going to continue struggling at that terms of reaching out to people that really need it. Plus, you've got the reluctance factor as well, as individuals are very independent. They generally won't seek help unless it's crisis situation.

The theme that caregivers do not see themselves as “caregivers” also arose in the hospital survey. One hospital representative suggested that some caregivers may be reluctant to adopt the label because they are in denial. Another respondent noted that some caregivers might be hesitant to admit that they need support as a caregiver because of the stigma associated with needing that support.

Current approaches in Michigan to marketing and outreach

Currently, there are several marketing and outreach approaches being employed to engage family caregivers in Michigan. The most common tactics utilized by the AAAs include social media utilization, posting flyers, both virtually and in places where caregivers may frequent (e.g., libraries, churches), and relying on word-of-mouth referrals from providers or support coordinators. Among the organizations surveyed, the most commonly used strategies to promote programs were word of mouth and referrals from community organizations, followed by fliers, social media, and referrals from healthcare providers.

One region stated that referrals from local physicians slowed down during the pandemic, likely due to a shift in clinician focus or individuals avoiding health care services during the pandemic out of fear of contracting COVID-19 at a doctor’s office. One AAA noted that the use of social media has increased the reach to more varied audiences, including younger caregivers who may not see fliers at locations such as senior centers, but are engaged on social media platforms. Some other methods that are used less frequently include mailings, newspaper and television ads, and cold marketing. The pandemic has had a detrimental impact on the effectiveness of in-person marketing approaches as in-person attendance in most settings has decreased significantly, rendering online marketing and outreach to be the best option. Even so, it can still be difficult for organizations to reach their target audience online. One major factor contributing to this is the notion that many family caregivers do not identify with the term “caregiver.” They more often view themselves in the context of their relationship with the care recipient as a sibling, child, friend, etc. who is just helping a loved one. Because of this, it is beneficial to utilize more inclusive language in marketing techniques that family caregivers may be more likely to identify with. This can be done by using descriptions of a caregiver’s duties or their role within their family structure. Organizations can also benefit from having dedicated staff for marketing and outreach efforts when possible.

Biggest challenges facing caregivers today

There are many challenges that family caregivers face today. Left unaddressed, these challenges can lead to caregiver burnout, which can have a detrimental impact on both the caregiver and the care recipient. The COVID-19 pandemic has made caregiving more difficult and has worsened many of the existing challenges that caregivers face.

These caregivers, although accustomed to providing the support to a family member or a friend, may now be doing it with children at home, because school is not in session [due to COVID-19]. So, the new ways that caregivers are having to adapt and maybe now the same task wears on them more than what it was before.

The following is a list of the biggest challenges facing caregivers today that were brought up by AAA interviewees, in order of most-frequently mentioned to least:

1. Isolation
2. Lack of understanding of available resources
3. Shortage and high turnover of paid caregivers
4. Don't seek supports early enough
5. Lack of respite options/long waitlists for respite programs
6. Managing childcare while caregiving
7. Managing employment while caregiving
8. Navigating care coordination
9. Transportation

Isolation was the most cited challenge facing caregivers today. Social isolation has long been a concern for seniors and caregivers, but during the COVID-19 pandemic, many conditions contributing to social isolation have been exacerbated. The reasons for this range from fears of contracting COVID-19, inability to participate in in-person activities, technological and connectivity barriers, in addition to loved ones not being able to visit and interact as usual. Many seniors and caregivers have expressed fears of participating in activities outside of the home, but in some cases, the feelings of loneliness caused by social isolation are so profound that some seniors have stated they would rather risk dying of COVID-19 than to go months without seeing their loved ones. The impact of social isolation on both caregivers and those being cared for was evident throughout the pandemic, and some AAAs even reported an uptick in service utilization early on as clients were feeling more alone and in need of connection.

"Social isolation, I mean that's huge right now... it was a hot topic before COVID, but now even exacerbated...I can't imagine being a caregiver, taking care of your loved one, and not being able to see or talk to your family...that social network you had before is pretty much gone. They're still trying to rebuild it now...Just because they say the pandemic is over, I don't think it [social isolation] is over. It's going to [impact] long-term, social, emotional, mental [health] for years to come."

Even before the pandemic, caregivers shouldered a heavy burden. Many caregivers balance taking care of their loved one with caring for children or grandchildren, as well as maintaining a household, career, and other responsibilities. The pandemic has made it more difficult for caregivers to find respite care for many reasons, including the shortage of direct-care workers, and the inability to have other outside assistance or family members come into the home to provide respite care out of fear of spreading COVID-19. One AAA described that in many families the responsibility of caregiving may be shared amongst family members, such as having the adult children help their mother care for their father. During the pandemic, the adult children may not be visiting their parents' home to assist them due to fear of spreading COVID-19. The lack of respite care and professional direct-care workers to provide assistance to caregivers has contributed to increased feelings of burnout, as caregivers need this assistance to participate in programming or even to get out of the house for everyday activities such as grocery shopping, visiting with friends, or participating in other self-care activities.

"I believe there's so many challenges caregivers face... but I think that the one that I can speak to and I hear often is the shortage of paid caregivers and the need for respite care. It has always been bad but pandemic-related, it's very difficult right now... paid-caregivers, there's very much of a shortage. They're paid very low, therefore the turnover is very high, so to get quality paid caregivers is extremely hard for families right now."

There's a \$2 an hour increase right now for direct care workers. I can't say that's even going to make a difference...direct care workers with older adults in-home is tough work. We almost need a societal shift of how we're going to take care of our older adults and maybe more leniency with employers and working with parents in the sandwich generation.

AAAs noted that even before the pandemic, they have seen caregivers die before the loved one they care for because of the physical, mental, and emotional burden the impact of caregiving may have. The burden on caregivers is heavier than before, and it is more difficult for them to set aside time for themselves or for self-care. Throughout the interviews, AAAs reported seeing increased anxiety and depression in caregivers throughout the pandemic, and many AAAs expressed that they believe these effects will last long after the pandemic is over.

Beyond the pandemic, a lack of understanding of what resources are available or who to reach out to for help is a common issue for caregivers. Caregivers not identifying with the term “caregiver” may play a role in this, as these individuals may not know that they are eligible to receive assistance through various caregiver programs. Relatedly, some caregivers also seem to be reluctant to reach out for support. Organizations often find that family caregivers come to them once they are in a crisis or at a breaking point. Some of the reasons that may be causing this is that many caregivers may neglect their own needs until they cannot anymore, they may feel the need to do their caregiving duties on their own, and the difficult fact that these conversations are very hard to have and to initiate. In addition to this, it can be hard for caregivers to find direct care help or respite with the current shortage of paid caregivers. This role has a very high rate of burnout and turnover due to the physically- and emotionally-demanding nature of the job and relatively low wages. Interviewees also noted that many caregivers must juggle childcare and/or employment in addition to their caregiving responsibilities.

From the survey of hospital organizations, the two most commonly identified challenges were caregiver burnout and caregivers’ lack of resources. A number of respondents described a connection between a lack of financial resources and caregiver burnout. For example, one respondent described:

They do not have enough money to be able to provide assistance with the demands of caregiving. They need respite/day care that they can afford. They often spend their own money to help support the person they are caring for.

Hospital representatives also described lack of social support, both from family and employers, as a factor that contributed to caregiver burnout.

Conclusions

Michigan AAAs implement several different types of evidence-based caregiver support programs, which most frequently include: BRI Care Consultation, Creating Confident Caregivers, Developing Dementia Dexterity, Powerful Tools for Caregivers, Savvy Caregiver, TCARE, and Trualta. Other programs and services are often available to help caregivers including additional aging and dementia education, support groups, counseling, in-home

supports and respite care. Many programs were halted, while a small number of others were adapted to online delivery due to COVID-19. AAAs generally indicated that they are able to meet the needs of caregivers who actively reach out for assistance, however, there is a large segment of the population who do not recognize their role as caregivers and are unaware of available community support services. This theme was also echoed in the organization and hospital surveys.

Recommendations for improving caregiver programs

1. A large-scale awareness campaign to reach people who do not recognize or are in denial that they are caregivers, educate them about the role, and connect them to supports they would benefit from. Estimates suggest that a considerable proportion of caregivers are not being reached by current caregiver programs and services in Michigan. In order to better serve this population, there is a need for a large-scale marketing and awareness campaign to help caregivers better recognize their role and connect them to available support programs and services in their communities. This campaign should use language that better frames the responsibilities of caregivers in an inclusive, and understandable way, and that is sensitive to the complexities of transitioning to the role of caregiver within the context of an existing relationship.

I don't think caregivers think of themselves as caregivers, if that makes any bit of sense. I think people need to understand what a critical role they play in their loved one's independence and they don't seek supports early enough in order to remain a consistent stable stress free or relatively stress free caregiver...We could do a lot more public education...to help the public know and give credit to informal and unpaid caregivers. [And help caregivers] so that they know what they might be able to access to help them in that role, or just to blow steam off and go have lunch with some other families that might be going through the same thing.

2. Develop more standard data collection measures to better inform decision-making, improvement processes, and reporting to programs at the local level. Given the lack of standard definitions, measures, and reporting requirements across the state for support programs, it is difficult to quantify the levels of caregiving services being provided, demographic profiles of those being served at each location, and the needs of caregivers at a local level^{lxxxiii}. Doing so will provide a more accurate picture of how programs are performing at the state and local level, help the aging network better quantify and project caregiver needs, and enable the development of strategies to better engage specific populations. In particular, data on caregiver characteristics such as race and ethnicity are an important tool for assessing the extent to which there is equitable access to caregiver programs and services. An important step towards achieving these aims will be to identify any potential barriers to the collection and reporting of data related to caregiver services and programs.

3. Continue to facilitate access to programs for marginalized groups and to ensure programs are inclusive and equitable. Many of the social movements and concerns about justice and equity over the last year have created new concerns and opportunities for conversation. Interviews suggest that there have been efforts in this area that are worthy of note. For example, one AAA has started offering new courses and programs on emerging issues for class discussion, such as COVID-19 long-haulers, Diversity Academy, LGBTQ community concerns, and other programs that cover topics on diet/nutrition and diversity, as well as other problems or concerns the “silent generation” may experience.

A scan of national studies on caregiving suggest that racial and ethnic minorities are less likely to utilize caregiver programs. Data limitations, such as missing race/ethnicity data and a lack of data on all caregiver programs, make it difficult to definitively say how well caregiver services and supports are reaching racial and ethnic minorities in

Michigan. Preliminary analyses suggest that Hispanic/Latinx caregivers are underrepresented in Older Americans Act (OAA) caregiver programs and services in Michigan; future work is needed to understand why this population is less likely to access these services, as well as to identify potential strategies for reaching this segment of the caregiver population. In addition, although preliminary analyses suggest Black caregivers are utilizing OAA caregiver services and supports in Michigan, there is a need for continued efforts to facilitate access to caregiver programs among this population—especially given that racial and ethnic minorities represent a priority population for OAA services and supports.

4. Support AAAs and other organizations as they navigate the logistics of integrating virtual and in-person program offerings post-pandemic. Moving forward, most AAAs indicated that they would likely utilize a combination of in-person and online offerings of programs as COVID-19 restrictions loosen. A lot of time and effort went into making these adaptations, and using a hybrid model should allow for more flexibility as well as help improve access to programs. In particular, virtual offerings may help improve the recruitment and engagement of younger caregivers who may be less able to attend in-person offerings due to competing work and childcare responsibilities. These organizations would benefit from resources that help identify barriers, strategies, and best practices for making this transition to a hybrid format. **In addition, improving high-speed internet access will be critical for supporting caregivers that seek to engage with programs online, as well as for promoting equitable access to caregiver services and supports.** Seniors, those living in rural areas, and those with limited financial resources may struggle to overcome technology barriers (including technological understanding and affordability of devices) - therefore any resources to facilitate the delivery of remote programs should aid this delivery model.

I do feel like a lot of our clients have been left behind because they do not even own a computer or any kind of piece of equipment with a camera, let alone know how to operate it. One of my goals, when I get back out into homes, is to really try to work with clients to help them learn how to access this platform. That way, if we're moving in this direction down the road [in] a more permanent way...they know how to purchase, and how to hook it up, and how to turn it on and all of that.

5. Increase workforce capacity, improve pay for direct care workers, increase training opportunities, and expand respite services in order to overcome barriers to participation in caregiver programs. AAA, organization, and hospital representatives discussed the need for additional resources and funding to increase staff capacity, improve the supply and pay of direct care workers, and expand respite services.

A lot has been moving and a lot of focus and attention, which I'm grateful for, and we need to keep up the momentum with direct care workers over the last year...to keep that \$2 an hour increase for direct care workers that's super helpful and it's necessary. If you could make \$15 an hour to be a barista versus \$11 an hour to have and have somebody in and out of a shower, what are you going to do when you're 22 years old and fresh out of college or in the middle of Grad school and need some extra money?...We have to incentivize this amazing work...it should be revered so much higher than it is.

[Re: direct care workers] fair pay for that staff. Right now we have the premium, where they are getting that \$2.25/hr hazard pay, but I think that very much needs to be looked at legislative-wise

as a permanent focal point, so we can have this incentive for quality people to apply and show our appreciation for what they do and their skills that are very much needed.

6. Expand funding specifically for caregiver related support programs and services in order to increase opportunities for caregivers to engage and overcome logistical barriers to participation, including innovative programs that seek to build novel partnerships and utilize new technologies to improve engagement and uptake of caregiver support programs. One AAA described with excitement the work they will be advancing in partnership with Henry Ford Health System to use mobile applications and social work programming to convene partners and families, with the goal of improving health outcomes, increasing efficiency, and delivering more support for caregivers (the project is funded through a Michigan Health Endowment Fund grant and titled “Closing the Loop for Seniors: A Pilot to Equip their Caregivers with Instructions & Support to Address Medical and Social Needs”). Increased funding of caregiver programs, broadly, would also allow for expanded program offerings, which could make participation more convenient. One respondent also introduced the idea of seeking reimbursement from employers or insurers for these types of programs in order to make them more sustainable.

I would also love a few more dollars in order to offer the programs more frequently, engage other community providers, so that we have broad coverage. We tend to use central locations in our rural areas, but if you [don’t want to take] almost an hour out of your day round trip to come just for an hour meeting, some people might not want to do that or leave their loved one alone that long. I would love to offer more broad programming and the funding would help support that, because then staffing could get enhanced or community providers could help us do it in other communities.

7. Create a state task force to ensure information is regularly gathered, updated, and disseminated to community organizations on evidence-based programs, best practices, evaluation measures, and tools. In order to better meet the needs of caregivers, AAAs also highlighted the need for greater opportunities to learn about the experiences of their peers in implementing these programs, including successes, challenges, and best practices. The aging network would benefit from a statewide task force that would regularly gather, update, and disseminate the latest information on evidence-based programs, best practices, evaluation measures, and tools. Moreover, this task force could advocate for legislative or administrative support to effect sustainable change, including mandating standardized data collection and reporting as mentioned above in recommendation #2.

8. Expand the reach of caregiver supports by developing new collaborations with health systems/hospitals, universities, AARP, the Alzheimer’s Association, and others⁸. Partnering with other community organizations, hospitals and universities could help organizations leverage additional resources and improve outreach efforts. One respondent stated that partnerships with local health systems had been particularly valuable on the recruitment front.

I think one of the biggest things that has helped the [recruitment for] evidence-based programs is the partnerships with health systems and other health centers. Instead of us always having to be the recruiter, we want to talk to people who are also invested in having folks improve those skills or gain that knowledge.

Conclusions

Michigan’s population, like the rest of the United States, is aging. As a result, the number of family and informal caregivers has increased substantially over the last three decades^{lxxxiii}. The needs of this population are unique. A

⁸ Recommendations 7 and 8 build on those put forth by Ilardo, J., King, S., and Zell, A. in their 2020 report titled *Analysis of the Responses to the 2020 Caregiver Resource Questionnaire for Michigan Area Agencies on Aging*.

large amount of caregiver support in Michigan is delivered through programs and services across sixteen AAAs. Caregiver programs can provide support in a host of ways including education, skill training, social and emotional support to caregivers, and connect individuals to valuable community resources. The levels of evidence associated with these programs vary, a great deal from those with a long history and rigorous evidence-base to the new and innovative. In Michigan, core evidence-based programs include: BRI Care Consultation, Creating Confident Caregivers, Developing Dementia Dexterity, Powerful Tools for Caregivers, Savvy Caregiver, TCARE, and Trualta (with additional dementia education, support groups, and services (including respite) being provided regularly at AAAs across the state.

COVID-19 has dramatically impacted both caregivers and support programs. Social isolation and caregiver burnout were exacerbated for caregivers everywhere due to stay-at-home orders, direct care worker shortages, and the lack of respite services being provided in the pandemic. Many AAAs reported that they were receiving more calls from caregivers during the pandemic than years prior. The delivery of many programs were halted until new modes could be effectively utilized and approved by program developers. Most respondents indicated that they were able to adequately meet the needs of those caregivers who reach out to them for support (although waitlists are present in some areas). However, a large number of respondents also indicated that there are a large number of caregivers who do not recognize themselves as caregivers and are largely unaware of the support services available to them. There are additional challenges to better serving caregivers through programs which include: staffing, overcoming logistical and technological challenges to both in-person and online delivery, restrictions to maintain fidelity, strategies to recruit caregivers and promote programs, and need for respite services and the direct care worker shortage.

Appendix A: AAA interview guide

Background

*The Center for Health and Research Transformation (CHRT) at the University of Michigan is collecting information on caregiver support programs for **unpaid family caregivers** in Michigan. We define these caregivers as someone who provides care or assistance for other adults in their lives. This can include things like running errands, helping out financially, taking them to appointments or helping around the house. Typically, these activities are unpaid, meaning a person does not receive any compensation for doing them. The care recipients may be family members, friends, neighbors, or anyone with whom the caregiver has a significant relationship.*

***Family caregiver support programs** typically provide educational training and resources and/or social and emotional support to caregivers. They often include education about health conditions, skills training, coping strategies, stress management tactics, connection to support groups, and respite.*

Interview

1. What are the name(s) of your organization's family caregiver support program(s)?
2. Could you please briefly description of your program? Note: If you have more than one program, please provide a short description of each.
 - a. Probe: target audience/population served, number of people served each year, program length, number of times offered each year
3. Is _____ a program your organization created internally or are you implementing an existing program developed by another organization?
 - a. Probe: Are you aware of the process in which the program was developed? Could you describe?
 - b. Probe: Reason for developing their own program?
4. How many staff are dedicated to supporting these programs (in full-time equivalents)? Background?
5. Could you tell us about how the program(s) is usually delivered: in-person, phone, online?
6. How has this changed in the pandemic? How do you see your program operating in the future?
7. How else has your program been impacted by the pandemic?
8. Are your current classes for _____ under capacity, at capacity, or over capacity?
9. Are these programs currently meeting the demands and needs of family and informal caregivers in your community?
10. Program strengths?
11. Program challenges? Barriers to participation?
12. What is needed to expand your program(s) to meet the demands and needs of your family and informal caregivers?
13. How is the program(s) funded? Do you have any concerns about sustainability?
14. Do you have any evaluation results of your programs? What were the results? Would you would willing to share with us?
15. What do you perceive to be the biggest challenges that family and informal caregivers face (e.g. understanding the plan of care, caregiver burnout, etc.)?

Appendix B: Community organization survey

Background

The Center for Health and Research Transformation (CHRT) at the University of Michigan is collecting information on caregiver support programs for **unpaid family caregivers** in Michigan. We define these caregivers as someone who provides care or assistance for other adults in their lives. This can include things like running errands, helping out financially, taking them to appointments or helping around the house. Typically, these activities are unpaid, meaning a person does not receive any compensation for doing them. The care recipients may be family members, friends, neighbors, or anyone with whom the caregiver has a significant relationship.

Family caregiver support programs typically provide educational training and resources and/or social and emotional support to caregivers. They often include education about health conditions, skills training, coping strategies, stress management tactics, connection to support groups, and respite.

This brief survey contains questions related to the work of organizations around Michigan which deliver support programs for family caregivers. The survey has a mixture of multiple choice questions and questions that will ask you to respond by typing in a number or a few words. The data will be collected through the online survey platform Qualtrics. Any identifying information will be removed before the data are analyzed and reported. Your answers to these questions will help us understand the needs and opportunities for family caregiver programs in Michigan. We greatly appreciate your participation!

Q1.2 What is your name?

Q1.3 What is your email address?

Q1.4 What is the name of the organization you work for?

Q1.5 What is your job title/role?

Q1.6 What geographic area does your organization serve?

Q1.7 Does your organization provide caregiving programs (either using its own staff or contracting out)?

Yes (1)

No (2)

Unsure (3)

Skip To: End of Survey If Does your organization provide caregiving programs (either using its own staff or contracting out)? = No

Skip To: End of Survey If Does your organization provide caregiving programs (either using its own staff or contracting out)? = Unsure

Demographics

Q2.1 Next, we'd like to get a general sense of the demographics of the people served by your organization's caregiving program(s).

Q2.2 Does your organization collect demographic information on caregiving program participants?

Yes (1)

No (2)

Don't know (3)

Q2.3 Please estimate the percentage of caregiving program participants in each of the racial categories below. If you don't know, please put an "X" in the don't know column.

	American Indian/Alaskan Native (1)	Asian/Asian American (2)	Black/African American (3)	Hawaiian Native/Pacific Islander (4)	White /Caucasian (5)	More than one race (6)	Other (8)	Don't know (9)
Percentage of program participants (1)								

Q2.4 Please estimate the percentage of caregiving program participants that are Hispanic/Latino.

Q2.5 Please estimate the percentage of the caregiving program participants in each of the educational levels below. If you don't know, please put an "X" in the don't know column.

Less than high school (1)	High school graduate/GED program (2)	Some college or technical/vocational training (3)	4 year college degree (4)	Graduate/professional degree/doctorate (5)	Don't know (9)
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Percentage
of program
participants
(1)

Q2.6 Please estimate the percentage of caregiving program participants in each age category below. If you don't know, please put an "X" in the don't know column.

Under 18 (1)	18-44 (2)	45-64 (3)	65-74 (4)	75 and over (6)	Don't know (7)
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Percentage of
program
participants
(4)

Q2.7 Please describe the gender profile of your caregiving program participants using the categories below. If you don't know, please put an "X" in the don't know column.

Male (1)	Female (2)	Other (6)	Don't know (7)
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Percentage of
program participants
(1)

Q2.8 Please describe the annual household income for participants in your caregiving programs using the categories below. If you don't know, please put an "X" in the don't know column.

Less than \$16,000 (1)	\$16,000- \$33,000 (2)	\$34,000- \$55,000 (3)	\$56,000- \$75,000 (4)	More than \$75,000 (5)	Don't know (6)
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Percentage of
program
participants
(1)

Q2.9 Please describe the employment status for participants in your caregiving programs using the categories below. If you don't know, please put an "X" in the don't know column.

	Working full-time (1)	Working part-time (2)	Unemployed or laid off and looking for work (3)	Unemployed and not looking for work (4)	Homemaker (5)	In school (6)	Retired (7)	Disabled, not able to work (8)
Percentage of program participants (1)								

Program information

Q3.1 What is the name of your organization's caregiver program? Note: We will ask questions about one caregiver program at a time. If you have more than one caregiver program, we will ask about additional programs in a later section of the survey.

Q3.2 Is \${Q3.1/ChoiceTextEntryValue} a program your organization created internally or are you implementing an existing program developed by another organization?

Developed internally (1)

Existing program from another organization (2)

Other (please describe) (3) _____

Q3.3 Please estimate the number of people \${Q3.1/ChoiceTextEntryValue} serves each year

Q3.4 Please estimate the percentage of participants who took \${Q3.1/ChoiceTextEntryValue} in-person, over the phone, and online **prior to the COVID-19 pandemic.**

% In-person (1)

% Over the phone (2)

% Online (3)

Percentage of participants
(1)

Q3.5 Please estimate the percentage of participants taking \${Q3.1/ChoiceTextEntryValue} in-person, over the phone, and online during the COVID-19 pandemic.

% In-person (1)

% Over the phone (2)

% Online (3)

Percentage of participants
(1)

Q3.6 Please estimate the percentage of participants you think will take \${Q3.1/ChoiceTextEntryValue} in-person, over the phone, and online after the COVID-19 pandemic.

% In-person (1)

% Over the phone (2)

% Online (3)

Percentage of participants
(1)

Q3.7 Do staff within your organization implement \${Q3.1/ChoiceTextEntryValue} or do you contract out?

Internal staff implement the program (1)

Contract out (2)

Both (3)

Q3.8 How many staff are dedicated to implementing \${Q3.1/ChoiceTextEntryValue}?

Q3.9 On average, how many total hours per week are spent by all the staff involved in implementing \${Q3.1/ChoiceTextEntryValue}?

Q3.10 Who typically implements \${Q3.1/ChoiceTextEntryValue}?

Social workers (1)

Nurses (2)

Community health workers (3)

Health educators (4)

Volunteers (6)

Other (please describe) (5) _____

Q3.11 What is the duration of one of the \${Q3.1/ChoiceTextEntryValue} cycles?

Q3.12 How many times each year do you typically implement \${Q3.1/ChoiceTextEntryValue}?

Q3.13 During a normal program cycle, how many people do you serve with \${Q3.1/ChoiceTextEntryValue}?

Q3.14 Are your current classes for \${Q3.1/ChoiceTextEntryValue}: under capacity, at capacity, or over capacity?

Under capacity (1)

At capacity (2)

Over capacity (3)

Q3.15 Are you able to meet the current demand from caregivers in your area regarding \${Q3.1/ChoiceTextEntryValue}?

Yes (1)

No (2)

Q3.16 If no, what would you need in order to expand your programming to meet caregiver demand? Please check all that apply.

Staff (1)

Physical space (2)

Information technology resources (3)

Financial resources (4)

Training and technical expertise (5)

Transportation assistance (6)

Other (please describe) (7) _____

Q3.17 How do you advertise \${Q3.1/ChoiceTextEntryValue}? Please check all that apply.

Fliers (1)

Word of mouth (2)

Radio ads (3)

Television ads (4)

Online ads (5)

Social media (Facebook, Twitter, Instagram, etc) (6)

Referrals from community organizations (7)

Referrals from health care provider (9)

Other (please describe) (8) _____

Q3.18 How would you rate the awareness of family caregivers in your area regarding the presence of \${Q3.1/ChoiceTextEntryValue}?

High (1)

Medium (2)

Low (3)

Don't know (4)

Q3.19 Does \${Q3.1/ChoiceTextEntryValue} focus on any special populations within your community? Please check all that apply.

People of color (1)

Younger caregivers (2)

Older caregivers (3)

LGBTQ+ (4)

Non-English speakers (5)

Women (6)

Men (7)

Military Veterans (9)

People with dementia (10)

People with intellectual and developmental disabilities (11)

Other (please describe) (8) _____

Q3.20 What are the biggest barriers that regularly prevent your program participants from participating in \${Q3.1/ChoiceTextEntryValue}?

Transportation issues (1)

Childcare issues (2)

Physical health problems for participant (such as chronic health problem, illness, injury, or disability) (3)

Physical health problems for a family member (such as chronic health problem, illness, injury, or disability) (4)

Schedule conflict with work/family schedule (5)

Mental or behavioral health problems for participant (such as depression or stress) (6)

Mental or behavioral health problems for a family member (such as depression or stress) (7)

Location of the programs (8)

Time the programs were offered (9)

Time commitment of the programs (10)

Financial issues (11)

Language barriers (13)

Other (please describe) (12) _____

Q3.21 Do you regularly track data to evaluate \${Q3.1/ChoiceTextEntryValue}?

Yes (1)

No (2)

Q3.22 If yes, would you be willing to share the results of \${Q3.1/ChoiceTextEntryValue} with us? We're interested in documenting the levels of evidence demonstrating the impact of caregiver programs in Michigan.

Yes (1)

Maybe (2)

No (3)

Q3.23 What key processes do you track to evaluate \${Q3.1/ChoiceTextEntryValue}? Please check all that apply.

Attendance (1)

Services provided (2)

Participant satisfaction (3)

Quality of program and services (4)

Resources used (5)

Participant background information (6)

Other (please describe) (7) _____

Q3.24 What key outcomes do you track to evaluate \${Q3.1/ChoiceTextEntryValue}? Please check all that apply.

Caregiver mental or behavioral health outcomes (1)

Caregiver physical health (13)

Care-related stress, strain or burden (9)

Efficacy, skills, or confidence in caregiving and/or symptom management (10)

Quality of the relationship with the care recipient (12)

Caregiver feeling supported (14)

Caregiver unmet need (15)

Caregiver quality of life/life satisfaction (16)

Support, information, community service use among caregivers (17)

Caregiver sleep quality (18)

Physical health outcomes of care recipient (2)

Mental or behavioral health outcomes of care recipient (3)

Other (please describe) (4) _____

Q3.25 How is the program funded? Please check all that apply.

Private insurance reimbursement (1)

Insurance reimbursement from Medicare or Medicaid (4)

Private fundraising (5)

Private donations (6)

Local millage (7)

State or federal grants (8)

Philanthropic grants (9)

Public donations (10)

Other (please describe) (3) _____

Q3.26 Do you have concerns about the long-term sustainability of the program?

Yes (10)

Maybe (11)

No (12)

Q3.27 If yes, please describe your concerns regarding sustainability.

Q3.28 Please describe any changes you've made to implement the program during the COVID-19 pandemic.

Q3.29 Does your organization offer any other caregiver programs?

Yes (1)

No (2)

Skip To: End of Survey If Does your organization offer any other caregiver programs? = No

Appendix C: Hospital survey

Background

The Center for Health and Research Transformation (CHRT) at the University of Michigan and the Michigan Health and Hospital Association (MHA) are collecting information on caregiver support programs for unpaid family caregivers in Michigan. We define these caregivers as someone who provides care or assistance for other adults in their lives. This can include things like running errands, helping out financially, taking them to appointments or helping around the house. Typically, these activities are unpaid, meaning a person does not receive any compensation for doing them. The care recipients may be family members, friends, neighbors, or anyone with whom the caregiver has a significant relationship. Family caregiver support programs typically provide educational training and resources and/or social and emotional support to caregivers. They often include education about health conditions, skills training, coping strategies, stress management tactics, connection to support groups, and respite. This brief survey contains questions related to the work of hospitals around Michigan which deliver support programs for family caregivers. The survey has a mixture of multiple choice questions and questions that will ask you to respond by typing in a number or a few words. The data will be collected through the online survey platform Qualtrics. Any identifying information will be removed before the data are analyzed and reported. Your answers to these questions will help us understand the needs and opportunities for family caregiver programs in Michigan. We greatly appreciate your participation!

Q1.2 What is your name?

Q1.3 What is your email address?

Q1.4 What is the name of the organization you work for?

Q1.5 What is your job title/role?

Q1.6 Does your organization provide family caregiver support programs (either using your staff or contracting the service out)?

☐ Yes (1)

☐ No (2)

Skip To: Q1.8 If Does your organization provide family caregiver support programs (either using your staff or cont... = No

Q1.7 What is the name of your organization's family caregiver support program(s)? Please provide a short description of the program. Note: If you have more than one program, please list them and provide a short description of each.

Display This Question:

If Does your organization provide family caregiver support programs (either using your staff or cont... = No

Q1.8 The MHA Keystone Center is evaluating the possibility of bringing a new family caregiver support program model to Michigan. Would your organization be interested in learning how to adopt this?

☐ Yes (1)

☐ No (2)

Skip To: Q1.17 If The MHA Keystone Center is evaluating the possibility of bringing a new family caregiver support... = Yes

Skip To: End of Survey If The MHA Keystone Center is evaluating the possibility of bringing a new family caregiver support... = No

Q1.9 How many staff are dedicated to supporting these programs (in full-time equivalents)?

Q1.10 Are these programs currently meeting the demands and needs of family and informal caregivers in your community?

☐ Yes (1)

☐ No (2)

Q1.11 What do you feel is the biggest strength of your program(s)?

Q1.12 What is needed to expand your program(s) to meet the demands and needs of your family and informal caregivers?

Q1.13 What do you perceive to be the biggest barriers that family and informal caregivers face (e.g., program participation, understanding the plan of care, caregiver burnout, etc.)?

Q1.14 What do you perceive to be the cause of this barrier?

Q1.15 How is the program(s) funded? Select all that apply

☐

Private insurance reimbursement (1)

☐

Insurance reimbursement from Medicare or Medicaid (2)

☐

Private fundraising (3)

☐

Private donations (4)

☐

Local millage (5)

☐

State or federal grants (6)

☐

Philanthropic grants (7)

☐

Public donations (8)

☐

Other (please describe) (9) _____

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