

Making the Invisible Visible: State Strategies for Identifying and Reaching Family Caregivers

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TAKEAWAYS

- Family caregivers — often relatives, friends, and neighbors — provide vital assistance to support the health and functional needs of older adults, but often face physical, emotional, and financial challenges related to their caregiving responsibilities.
- Many states are seeking to better support this important workforce, particularly family caregivers in communities of color, but need an effective way to accurately identify the number, diversity, and unique needs of family caregivers in their state.
- In identifying family caregivers, states should recognize cultural considerations, including distinct racial and ethnic perspectives associated with caregiving, that may have implications for identification.
- This brief presents key strategies to help states better identify and reach family caregivers, drawing on state examples from the [Helping States Support Families Caring for an Aging America](#) initiative.

In the U.S., approximately 41 million Americans serve as a caregiver for an older adult.¹ These individuals are typically relatives, friends, and neighbors who provide ongoing assistance to adults aged 50 or older with health and functional needs. That number, however, is likely *much* higher since so many family caregivers do not identify themselves as such.

When it comes to caring for others, for many people, it is simply what you *do*. Caring for another is what it means to be a good spouse, child, grandchild, or friend. For certain racial and ethnic communities, there may not even be a word for “caregiving” in their languages.² Yet, while the idea of seeking support for — or relief from — caregiving responsibilities is rarely top of mind for people in this role, caregiving often takes an enormous physical, emotional, and financial toll.³

Given the growing number of family caregivers in the United States coupled with the impact of the COVID-19 pandemic in highlighting their critical role in caring for older adults, states are realizing the importance of family caregivers to the U.S. health care system and society as a whole.⁴ Many states are seeking to more effectively address the

health, economic, and social challenges experienced by family caregivers, especially those from marginalized communities. However, not having an accurate grasp on the number, diversity, and distinct needs of family caregivers across a state can make efforts to support them more difficult. In many states, gaps exist between the number of family caregivers and services accessed. In Michigan, for example, the use of respite care remains low despite the known need from family caregivers.⁵ Accurately identifying family caregivers is a vital first step for states to promote available family caregiver supports and develop policies and programs that address the unique needs of all caregivers. States also need to recognize cultural considerations, including distinct racial and ethnic perspectives associated with caregiving, that may have implications for identification.

This brief outlines practical strategies to identify and reach family caregivers pursued by cross-sector state teams participating in [Helping States Support Families Caring for an Aging America](#), a Center for Health Care Strategies (CHCS) initiative made possible by The John A. Hartford Foundation and the Michigan Health Endowment Fund. For the participating teams — comprised of Medicaid, Departments of Aging and Health and Human Services, Area Agencies on Aging (AAAs), universities, health plans, and community-based organizations — helping family caregivers access supports and services is a high priority.

Four Key Strategies to Identify and Reach Family Caregivers

The following strategies, drawn from the experiences of states participating in CHCS’ initiative, prioritize approaches that meet individuals where they are, with examples highlighting how states have strengthened identification and supports for family caregivers, particularly in communities of color. These examples can help inform state efforts to effectively identify and support this often “invisible” workforce. However, there is no one-size-fits-all solution for identifying and reaching family caregivers, and state context should be considered.



1. Embed processes to identify family caregivers through state agencies and public-private partnerships, rather than waiting on family caregivers to self-identify.



2. Prioritize stakeholder education to ensure that approaches for identifying family caregivers are responsive to specific state and community context.



3. Tailor outreach strategies and build trust to reach specific caregiver populations.



4. Leverage caregiver assessments, surveys, and tools to support identification, data collection, and service delivery.

1. Embed processes to identify family caregivers through state agencies and public-private partnerships, rather than waiting on family caregivers to self-identify.



Individuals who are unaware that the care they provide is considered “caregiving” are highly unlikely to self-identify as a family caregiver. Instead of placing the onus on family caregivers to seek support, states can consider developing processes that allow for more organic opportunities for identification that meets families where they are.

- **Identify family caregivers through workforce connections.** Working family caregivers⁶ juggle both professional and family caregiving responsibilities and are often at high risk of burnout and leaving the workforce. The **New York** State Office for the Aging, the New York State Department of Labor, and the New York State Department of Health launched a public-private partnership to survey businesses⁷ and their employees with the goal of identifying and reaching family caregivers in the workforce. The state encouraged employers to help identify the number of employees who are caregiving for a loved one, assess working caregiver stress levels, and connect them to supports and information. The state also provides a Caregiver Guide to Businesses⁸ to employers statewide to help working family caregivers find support and resources. A Working Caregiver Fact Sheet⁹ was also developed to highlight the impact of caregiving in the workplace.
- **Identify family caregivers through AAA networks.** In partnership with the state’s AAA’s, the **Iowa** Department on Aging implemented a standardized family caregiver assessment¹⁰ in January 2020. Designed to be a short assessment administered by AAA staff, the process allows for a quick snapshot of the family caregiver’s current situation and pressing issues to help document needs and help guide service provision. Iowa has found that collecting consistent, meaningful data across different regions of the state has highlighted service gaps and identified family caregivers they are not currently serving, creating opportunities to improve program design.
- **Build public awareness to help caregivers self-identify.** To reach more family caregivers and encourage them to take advantage of available services and supports, **Texas** is planning a public awareness campaign. They hope to connect with more family caregivers across the state by tailoring the campaign for particular audiences, including older adults and people from marginalized communities. Similarly, **Washington State** adopted the Amherst H. Wilder Foundation’s “We Call it Caregiving” outreach campaign,¹¹ originally developed for Minnesota, to help caregivers self-identify, using images of diverse populations to resonate with

various caregivers. AAAs in Washington were also able to use the images and campaign materials within their local communities to reach caregivers. The state ultimately found that some of the more effective methods were billboards, bus advertisements, newsletters, and ads in the preview content in movie theaters.

- **Provide useful resources to support identification.** The AAA in Cortland County, **New York**, developed family caregiver packets for hospital discharge planners across the county. The packets help inform family caregivers about the discharge process and support a smooth transition home for caregivers and their loved ones. Once the AAA began disseminating the resource, it saw a significant increase in referrals, particularly for individuals leaving rehabilitation facilities and needing family support in the home. Other AAAs throughout the state have replicated the family caregiver resource packets and found that they have been helpful in encouraging new family caregivers to self-identify, with an increased number of caregivers contacting AAAs for support.

2. Prioritize stakeholder education to ensure that approaches for identifying family caregivers are responsive to specific state and community context.



States can provide stakeholder education to help tailor identification and outreach strategies to specific communities to better address the identified needs of family caregivers. Educating key stakeholders — including staff from AAAs, managed care organizations (MCOs), and state agencies — on the best approaches for talking to family caregivers is one way that states can support ongoing self-identification.

- **Engage dual-eligible special needs plans (D-SNPs) to support family caregivers.** Staff from the **Washington** Department of Social and Health Services and AAAs are partnering with D-SNPs in the state to recognize the role and needs of family caregivers. The focus of the partnership is for the plans to support providers in learning to identify unpaid family caregivers of members in clinic and hospital settings and expand access to services for those caregivers.
- **Leverage AAAs' unique position to identify family caregivers.** **Iowa's** Department on Aging encourages AAA staff to ask about family caregivers at every available opportunity. When an individual calls an Iowa AAA to ask for support or resources, staff are trained to say, “are you calling about yourself or for someone else?” to help prompt a conversation and potentially identify a family caregiver.
- **Create specific roles to support family caregivers.** The **Minnesota** Board on Aging and Department of Human Services, in partnership with AAAs, routinely offer training to staff to certify them as Caregiver Consultants¹². Caregiver Consultants

provide support to family, friends, and neighbors who are caregiving through assessment, goal setting, action planning, and continued follow-up. As part of their consultation, Caregiver Consultants connect family caregivers to available services in the state’s aging network, provide one-on-one support and education on caregiving skills and self-care, and more. The Caregiver Consultants program reflects the Minnesota Department of Human Services and the Board on Aging’s commitment to maximizing state resources to ensure all Minnesotans who are caregivers can have their needs met.

- **Acknowledge family caregivers’ personal perspectives and needs.** In **Michigan**, groups including the AAA Association of Michigan, Michigan Bureau of Aging, Community Living, and Supports, AARP Michigan, Michigan State University, University of Michigan Alzheimer’s Disease Research Center, and Universal Dementia Caregivers make it their mission to understand the unique needs of family caregivers. These organizations provide messaging and approaches to help their staff embrace caregivers’ desires to address their family’s distinct needs and perspectives, including starting conversations with “we see you, and we respect your service and commitment.” This philosophy helps the state increase access to supports for a broader array of family caregivers, including those from under-resourced communities.
- **Recognize that culture often shapes family caregiving.** When states take steps to educate their staff, it is critical to respect diverse perspectives and enter conversations with cultural humility. State staff should seek to identify family caregivers’ unique viewpoints since the act of caregiving is often shaped by individuals’ cultures, family dynamics, and values. In **Tennessee**, the state’s Medicaid program (TennCare) and the three MCOs in the state — Amerigroup, United Healthcare, and Blue Care — came together to leverage knowledge from diverse populations to shape the MCOs’ family caregiver outreach strategies. For example, some cultures value caring for their family members at home, so the MCOs focus interactions with those populations primarily on education around home- and community-based services available that can support both the individual and the family caregiver.

3. Tailor outreach strategies and build trust to reach specific caregiver populations.

Many states recognize that traditional approaches to supporting family caregivers are often developed from a white-culture perspective and, therefore, may not resonate with caregivers in communities of color. Tailored strategies that recognize the strengths of these populations and prioritize their perspectives on family caregiving are critical.



Successfully reaching family caregivers requires identifying — and then meaningfully partnering with — the individuals and populations that have been marginalized by inequitable state and federal policies. Knowing the gaps and any barriers for identifying caregivers is a critical first step to developing intentional approaches that best support these populations.

- **Listen to older adults and family caregivers.** **Indiana** established an Older Hoosier and Caregiver Advisory Group¹³ comprised of older adults and family caregivers who provide recommendations on approaches to effectively engaging their own populations throughout the state. The group relies on a strong relationship with the Indiana Minority Health Coalition, which provides input on how meetings are planned, conducted, and communicated to maximize the participation of diverse family caregivers.
- **Look to community partners for the best insights into reaching family caregivers in diverse populations.** **Washington State** realized that only a small percentage of family caregivers of color in the state are using available supports and services. In trying to increase the number of family caregivers who self-identify, Washington is exploring strategies to broaden the aging network’s ability to support self-identification in communities of color. AAAs throughout the state partner with community or faith-based organizations that serve communities of color to get the word out, often contracting with them to administer programs.
- **Prioritize building trust with the community.** **Washington** Department of Social and Health Services’ longstanding relationship with the state’s network of AAAs, a local, trusted resource, has helped the state succeed in serving the health and social needs of families, including family caregivers. In King County, because of the AAA’s well-established reputation, community members have long felt comfortable approaching them, especially when seeking supports and services for family caregivers. The City of Seattle AAA contracts with a diverse network of programs and administering agencies that are well known in their communities, such as Asian Counseling and Referral Services, Jewish Family Services, GenPride, Neighborhood House, Alzheimer’s Association, and many others. Given their discrete community-based locations, knowledge of local resources, and developed relationships within their communities, AAAs across Washington are well-positioned to help support caregivers within their communities.

4. Use caregiver assessments, surveys, and tools to support identification, data collection, and service delivery.



Standardizing and formalizing approaches to better identify and understand family caregivers can help states more effectively deliver services. Statewide assessments, and surveys and are some approaches that states can take to better serve a growing number of family caregivers.

- **Use already existing assessments.** Two of **Tennessee's** MCOs use TCARE¹⁴ — a platform that continuously processes stressors in a family caregiver's life and offers care plans and local resources. The tool has helped MCOs ensure that family caregivers are considered in addition to the care recipient. MCOs using TCARE have found it particularly helpful in capturing data about the population. Tennessee plans to build on the utility of these tools, including aligning them with internal processes and streamlining the state's overall assessment and data infrastructure.
- **Bring diverse voices and perspectives together to shape and redesign processes.** A key step in ensuring the success of surveys, assessments, and other tools is making them accessible to a wide variety of individuals, particularly family caregivers of color. To improve uptake of its TCARE assessment, **Washington** held a summit to gather the perspectives of Vietnamese and Korean family caregivers and inform a more tailored approach for administering the tool. In talking to community members, the state found that the process is more effective when the assessment is administered by a provider the community trusts, especially when English is not the first language of the community.

Conclusion

As states seek to improve family caregiver supports and services, doing so successfully requires understanding who caregivers are and using that knowledge to tailor approaches to identifying and reaching them. It can be difficult, however, for states to identify and connect with family caregivers. In particular, effectively identifying and communicating with family caregivers can be more challenging when reaching different racial and ethnic populations due to varying cultural perspectives associated with caregiving and related implications on self-identification. By developing strategies that allow family caregivers to better access supports and services, including those for communities of color, states will be able to more confidently provide meaningful support to meet the needs of all family caregivers. Other states can adapt the lessons shared in this brief to their own approaches for identifying and reaching family caregivers.



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ENDNOTES

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- ¹¹ For more information on the Amherst H. Wilder Foundation’s outreach campaign, see: Caregiver Awareness. Available at: <https://www.wilder.org/what-we-offer/healthy-aging-caregiving-services/caregiver-services>.
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- ¹³ Indiana Family and Social Services Administration. “Older Hoosier and Caregiver Advisory Group.” Available at: <https://www.in.gov/fssa/long-term-services-and-supports-reform/stakeholder-engagement/older-hoosier-and-caregiver-advisory-group/>.
- ¹⁴ For more information on TCARE, visit: <https://tcare.ai/>.