

Establishing Cross-Sector Partnerships to Improve Family Caregiver Supports

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TAKEAWAYS

- As the aging population continues to grow, there is a greater need for states to provide supports for the increasing number of family caregivers.
- Cross-sector partnerships can help state agencies, health plans, community-based organizations, researchers, advocates, and other organizations better support family caregivers by avoiding duplicative efforts, using resources more efficiently, and expanding the number of caregivers served.
- This tool can inform states interested in pursuing cross-sector partnerships to strengthen supports and services for family caregivers. It features examples from participants in the Center for Health Care Strategies' initiative, [Helping States Support Families Caring for an Aging America](#).

In recent decades, older adults in the United States have increasingly sought to age at home, leading to more family members, friends, and neighbors stepping in to help loved ones live comfortably in their own homes and communities.¹ With the nation's growing aging population, the need for family caregiver supports and services — such as respite care, care coordination, options counseling, training, and support groups — has never been greater.

State agencies, including Medicaid agencies, Departments of Aging, and Health and Human Services, typically provide a variety of supports for family caregivers, but it is difficult for states to support caregivers alone.² Challenges facing states in effectively supporting caregivers include a lack of data about the caregiver population, limited ability to reach diverse family caregivers and those in rural regions, and the need to streamline family caregiver assessments. Health plans, community-based organizations, Area Agencies on Aging (AAAs), and researchers also play an important role in supporting family caregivers, but often work in silos from each other and from state agencies. Cross-sector partnerships can help states reach more caregivers, avoid duplicative efforts, and use resources more effectively.³



The Center for Health Care Strategies’ (CHCS) [*Helping States Support Families Caring for an Aging America*](#) initiative, supported by The John A. Hartford Foundation and the Michigan Health Endowment Fund, helped eight states foster cross-sector partnerships and identify which agencies, departments, and community-based organizations should be at the table to best support caregivers. For many of the states, this involved working with non-governmental organizations such as AAAs, Alzheimer’s Association chapters, and AARP state offices (see Exhibit 1). These cross-sector efforts enabled the participating states and their partners to build on and synergize work already in progress, resulting in more creative and collaborative strategies to support caregivers.

This tool can help guide states interested in forming cross-sector partnerships with external stakeholders committed to strengthening supports and services for family caregivers. The recommended strategies feature examples from the states that illustrate how partnerships can be implemented to better support family caregivers.

Exhibit 1. Cross-Sector Teams in Helping States Support Families Caring for an Aging America

STATE	CROSS-SECTOR TEAMS
Indiana	Office of Medicaid Policy & Planning, Family and Social Services Administration; Division of Aging, Family and Social Services Administration; Indiana State Department of Health; AARP; Seniorlink/Caregiver Homes
Iowa	Iowa Department on Aging; Aging Resources of Central Iowa; Northeast Iowa Area Agency on Aging
Michigan	Michigan Department of Health and Human Services Bureau of Aging, Community Living, and Supports (ACLS Bureau); AARP Michigan; Area Agencies on Aging Association of Michigan; Michigan State University, College of Human Medicine and School of Social Work; University of Michigan Alzheimer’s Disease Research Center; Universal Dementia Caregivers
Minnesota	Minnesota Board on Aging; Minnesota Department of Human Services Aging and Adult Services Division; Minnesota Department of Human Services; Minnesota Council of Health Plans/HealthPartners; Alzheimer’s Association Minnesota
New York State	New York State (NYS) Office for the Aging; NYS Caregiving and Respite Coalition; NYS Office for People with Developmental Disabilities; NYS Department of Health, Office of Primary Care and Health Systems Management; NYS Division of Veterans’ Services; NYS Kinship Navigator; AARP NY; Alzheimer’s Association, NYS Coalition
Tennessee	Division of TennCare, Long-Term Services and Supports; Amerigroup and Anthem Company; BlueCare Tennessee; UnitedHealthcare Community Plan, Tennessee
Texas	Texas Health and Human Services; Texas Governor’s Committee on People with Disabilities; AARP Texas; Texas Association of Regional Councils
Washington State	Aging and Long-Term Support Administration, Home and Community Services Division, Department of Social and Health Services; Washington State Health Care Authority; Washington Association of AAAs; Southeast Washington Aging and Long-Term Care (representing Washington Association of AAAs [W4A]); Office of the Governor

Recommendations for Establishing Cross-Sector Partnerships

Following are recommendations to guide states in establishing cross-sector partnerships, illustrated by state examples. These strategies do not need to be followed in any specific order. States are encouraged to choose activities that are best suited for their specific context and partnership opportunities.

1. Conduct an environmental scan.

It is critical for state agencies to understand existing work across a state focused on family caregiving, including the players involved and any opportunities for partnerships to enhance the work. Environmental scans can identify an inventory of programs that are effective in supporting caregivers and uncover gaps in services and other potential avenues to explore. Since some, if not all, of the groups in a partnership may be coming together for the first time, a statewide scan provides a valuable foundation regarding work, programs, and/or research underway.



The **Indiana** team began their partnership by taking an inventory of existing statewide family caregiver assessment tools. This activity identified what assessment tools were already being used by other agencies and organizations and helped reveal any duplication and gaps. Going forward, the team will develop a standardized caregiver needs assessment that includes best practices identified in the scan for all partners to use.

2. Define roles and responsibilities as soon as possible.

Each organization or agency should identify its unique role and contributions within the cross-sector team to maximize organizational strengths and opportunities. One state agency typically serves as the designated team lead with the other organizations offering tailored expertise and support through research, advocacy, or community work. Exhibit 2 details the unique strengths that each type of organization can bring to a partnership.



The **Tennessee** team is seeking to implement a standardized assessment to measure family caregiver stress and burden. TennCare, Tennessee’s Medicaid agency, is leading this effort and had a set of standardized, core questions related to stress and burden that could be used as a baseline. TennCare partnered with representatives from the three Tennessee managed care organizations (MCOs), which established a workgroup to review and refine the core questions and will be administering the assessment. In this

example, TennCare led the effort in partnership with MCOs to create an assessment to better meet the needs of members who are caregivers.

Exhibit 2. Examples of Organizational Roles in a Partnership

ORGANIZATION TYPE	EXAMPLE	ROLE IN PARTNERSHIP
State Agency	Medicaid, Division on Aging, Department of Health and Human Services	Offer federal, state, and local funding opportunities; serve as information hub to support existing and future work; implement policies for caregiver supports, like respite; lead and/or organize the cross-sector partnerships.
Community-Based Organizations	AARP, Alzheimer’s Association, Area Agencies on Aging	Provide supports, services and resources to family caregivers; offer deep connections to the community and needs of family caregivers.
Managed Care Organizations and Health Plans	Amerigroup, UnitedHealthcare, Council of Health Plans	Assess caregiver needs and make referrals to service providers or offer services themselves, like caregiver trainings and education materials.
Universities/ Research Groups	Michigan State University, University of Michigan Alzheimer’s Disease Research Center	Conduct environmental scans, data collection, and analysis; measure and provide a full picture of the caregivers’ current needs and recommend strategies to address identified needs.

3. Develop a partnership team structure that prioritizes action and consistent communication across the organizations.

Hold regular meetings to build supportive relationships based on trust, accountability, aligned interests, and frequent collaboration. This routine communication will help ensure the work is streamlined and continues to move forward. Open and consistent communication can help identify and overcome potential hurdles at the outset of the cross-sector team’s formation. Within the partnership team structure, distinct workgroups can be created to address specific priority issues. Anticipating possible speedbumps such as staff turnover, shifting priorities, limited budgets, and busy schedules provides an opportunity for team members to be transparent with each other about mitigating identified issues.



The **Texas** team established two workgroups to focus on separate goals around a family caregiver public awareness campaign and a toolkit for enhancing existing family caregiver supports. Each workgroup meets regularly to work toward their goals. The groups set project objectives early on and have developed workplans and assignments based on each team member’s specific expertise. These strategies have contributed to the sustainability of the workgroups’ progress and successes. For example, Texas’ caregiver public awareness campaign workgroup provided support and expertise to an American Rescue Plan Act funding proposal that resulted in Texas receiving the funding.

4. Establish a shared definition of success.

Family caregiving is a broad topic area and teams may feel overwhelmed by the many directions their work could take. Establishing a *common* goal at the outset helps focus the partnership’s efforts on an attainable objective, such as creating a clearinghouse for caregiver resources or implementing a caregiver assessment for the states’ AAAs to distribute. With different organizations providing expertise, the work becomes richer and there are more opportunities for meaningful progress.



The **Tennessee** team consists of a strong partnership between TennCare and the state’s three MCOs. The shared goal is for all the MCOs to offer one standardized, mutually agreed-upon assessment that measures stress and burden to help shape caregiver supports. This team created a uniform approach for assessing family caregiver stress and burden. When the team formed, each MCO had their own family caregiver stress/burden assessment, so the MCOs worked together to compare the assessments to identify the strongest questions and make improvements as necessary. Creating one assessment will allow all three MCOs to share one method of analyzing caregiver stress and burden to ensure a consistent and streamlined assessment process moving forward.

5. Share resources.

Working in a partnership enables cross-sector teams to share their expertise, resources, and networks, and expand their reach and impact. Collaboration across agencies creates an opportunity to combine resources to support caregivers more effectively. States can think strategically about the types of organizations to involve in supporting caregivers and what knowledge gaps they can fill, including expertise in advocacy, research, and policy.



The **New York State** team is focused on reaching family caregivers in the workforce and strengthening supports for this population.⁴ In June 2021, 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 survey for employers of all sizes and sectors across the state. The survey sought to identify family caregivers in the workforce to provide them with services and educate employers on this unique population on their payrolls. The New York cross-sector team, comprised of various state agencies and community-based organizations, is pooling resources to continue to disseminate the survey broadly. They also created a Caregiver Guide for Businesses⁵ to help employers better support family caregivers in the workplace. Together, the team will be able to expand their reach to

employers in the state and share the survey with more family caregivers than they would have separately.

Conclusion

Forming cross-sector partnerships is a critical strategy for states eager to pursue meaningful ways to support family caregivers and strengthen and shape policies and programs. State agencies, and the family caregiving-related organizations they work with, will see more significant progress by working together instead of in silos. This work takes time, but with thoughtful preparation and strategic planning, cross-sector partnerships can be successfully formed and sustained over the long term.



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ENDNOTES

¹ Centers for Disease Control and Prevention. “Caregiving for Family and Friends — A Public Health Issue.” Available at: <https://www.cdc.gov/aging/caregiving/caregiver-brief.html>

² E. James and M. Hughes. *Embracing the Role of Family Caregivers in the U.S. Health System*. Health Affairs Forefront, September 2016. Available at: <https://www.healthaffairs.org/doi/10.1377/forefront.20160908.056387/full/>

³ C. Roman, M. Ralls, and G. Torralba. *Strengthening Family Caregiving Programs and Policies through Collaboration: Lessons from Six States*. Center for Health Care Strategies, September 2020. Available at: <https://www.chcs.org/resource/strengthening-family-caregiver-programs-and-policies-through-collaboration-lesson-from-six-states/>

⁴ C. Roman, S. Bane, and E. Opthof. “How Employers and States Can Support the Essential Workforce of Family Caregivers.” *American Journal of Health Promotion*. 35, no. 7 (2021): 1045-1047. Available at: <https://www.chcs.org/how-employers-and-states-can-support-the-essential-workforce-of-family-caregivers/>

⁵The New York State Office for the Aging and the New York State Department of Labor. “Caregivers in the Workplace: Finding Balance for your Employees.” May 2022. Available at: <https://aging.ny.gov/system/files/documents/2022/07/caregivers-in-workplace-guide-2022.pdf>