

Involving Family Caregivers to Shape Multisector Plans for Aging

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KEY TAKEAWAYS

- Multisector plans for aging (MPAs) — also called master plans, strategic plans, and aging well plans — are state-led, cross-agency, and stakeholder-engaged strategic planning resources that can help states align and transform services for older adults and people with disabilities.
- Since family caregivers provide the majority of care for older adults and individuals with disabilities, it is critically important for states to involve family caregivers in the development of their states' MPAs and ensure that the MPA includes priorities and initiatives that address the needs of family caregivers.
- This tool describes: (1) how states can engage family caregivers in shaping and implementing an MPA; (2) concrete strategies to support family caregivers in MPA development activities; and (3) examples of language used in MPA initiatives focused on family caregivers from two states (Minnesota and Texas).

A multisector plan for aging (MPA) is a state-led, cross-agency, and stakeholder-engaged strategic planning resource that can help states transform the coordination of services for older adults and people with disabilities.^{1,2}

MPAs are designed to address the needs of everyone in the state across the aging and/or disability continuum — family caregivers, younger people planning for retirement, people aging with disabilities, and/or adults over age 65 — as well as industries serving older adults and businesses that employ older adults or family caregivers. State agencies that support older adults and people with disabilities (e.g., Departments on Aging, Health and Human Services, Medicaid agencies) often lead the MPA development effort, but many other state agencies that provide vital services for these populations, like Area Agencies on Aging and AARP, are also engaged. MPAs should also meaningfully integrate the voices of the people providing daily care for older adults — family caregivers.

Family caregivers should play an integral role in shaping MPAs because they play a vital role in contributing to the well-being of older adults and people with disabilities. For example, older adults prefer to live in their homes and communities as long as possible, and to do that they often need the support of family caregivers.³ As a result, the number of



family caregivers caring for older adults continues to rise dramatically — there has been an increase 7.6 million family caregivers since 2015, bringing the total to approximately 53 million.⁴ More than half of all family caregivers are between the ages of 50-75,⁵ providing both the perspective of older adults as well as the caregiver role. They also contribute substantially to the health care sector, with family caregivers' unpaid care estimated at roughly \$470 billion annually.⁶ Family caregivers spend countless hours navigating state services for themselves and their loved ones and will know what works, what does not, and where gaps exist. Being that family caregivers are so involved in the wellbeing of older adults, they should be consulted in this work. Notably, more than 60 percent of family caregivers are women, often women of color.⁷ The underlying disparities facing women of color make the challenges of family caregiving even more difficult. Thus, as states look to develop MPA strategies that can improve health and promote greater health equity, it is critically important to engage family caregivers, and particularly family caregivers of color, to best understand their perspectives.

This tool, developed by the Center for Health Care Strategies (CHCS) with support from The John A. Hartford Foundation and the Michigan Health Endowment Fund, describes strategies states could use to engage family caregivers to shape and implement an MPA. It also lists considerations for how MPAs can prioritize family caregivers and includes examples of language on family caregivers used in MPAs in two states — Minnesota and Texas — that participated in CHCS' *Helping States Support Families Caring for an Aging America* initiative.⁸

Integrating the Voices of Family Caregivers into MPA Development

An MPA that is shaped by lived experience is more likely to successfully meet the needs of older adults, individuals with disabilities, family caregivers, their communities, and meet state policy goals. Following are strategies states could pursue to involve family caregivers in MPA development, illustrated by examples from CHCS' *Helping States Support Families Caring for an Aging America* learning collaborative.

- **Gather meaningful data on the lived experiences of family caregivers** through listening sessions, interviews, and surveys. Design survey questions to obtain demographic data (e.g., geography, race/ethnicity, sexual orientation/gender identity, socioeconomic status, etc.) and collect feedback from family caregivers on the supports that they need, challenges they experience, and what they enjoy about being a family caregiver. For example, the **Texas Health and Human Services Commission** surveyed older adults, family caregivers, and service providers to identify what they believe are the main needs and priorities of family caregivers. Those results were used to shape the Aging Texas Well Strategic Plan.⁹



- **Include a diverse range of family caregivers** from different backgrounds, races and ethnicities, genders, age groups, and income levels to ensure a focus on equity and inclusion in the MPA. Because the term “family caregiver” is not used in all racial and ethnic communities,¹⁰ states should develop strategies to engage family caregivers from diverse populations. For example, in **Minnesota**, initiatives like Wisdom Steps,¹¹ a preventive health program designed by Native American elders, are in place to work with cultural and ethnic communities to better meet the needs and preferences of those in their community who are providing care as well as the individuals receiving care.¹² The Diverse Elders Coalition recommends adding more inclusive language into resources on who qualifies as a family caregiver, investing in resources to overcome language and cultural barriers, and prioritizing translated materials.¹³
- **Hold listening sessions with family caregivers** to gather their perspectives on services that work well for older adults and people with disabilities, as well as gaps in services and challenges they face. In **Indiana**, public sessions with family caregivers helped state leadership understand family caregivers’ requests for more respite, education, and other supports to help them keep their loved ones safely in their homes and avoid institutionalized care.¹⁴
- **Partner with community-based organizations** to conduct outreach and identify family caregivers to participate in strategic planning meetings, listening sessions, interviews, etc. for MPAs. In **California**, the Department on Aging partnered with the Alzheimer’s Association and local family caregiver resource centers to conduct conference calls in a variety of languages for family caregivers on priority topics such as infection prevention, nursing home visitation, and grief. Activities like this offer opportunities for state staff to hear directly from family caregivers to help shape the MPA.



Prioritizing Family Caregivers in MPAs

Given its cross-sector approach, there are numerous opportunities throughout an MPA for states to center family caregivers’ needs and prioritize strengthening supports and services. Below are considerations for how MPAs can prioritize family caregivers in common sections of MPAs, which include labor, health, environment, and the direct care workforce. These considerations are not listed in any particular order of prioritization.

- **Help support working family caregivers and the industries that employ them.** With more than 60 percent of family caregivers employed full time, there is a significant need to help employers understand and implement meaningful strategies to support working family caregivers. As many industries face worker shortages, it is imperative to help employers retain and recruit workers who are caregivers. An MPA could describe tangible steps the state could take to support working family caregivers, including developing paid leave laws,¹⁵ providing tools



and resources to employers (such as **New York's** Caregiver Guide for Businesses¹⁶ or **Colorado's** efforts to promote Age Inclusive Management Strategies¹⁷), and encouraging flexible work hours and schedules so working family caregivers are better able to balance their work and caregiving responsibilities.¹⁸

- **Promote initiatives that support the health and well-being of family caregivers.**

Across the country, family caregivers often report their health has worsened¹⁹ because of their caregiving responsibilities. Family caregivers may forgo seeing health care professionals,²⁰ even when they are sick or have health concerns, because they do not have any other options for caring for their loved one. Additionally, the stress of caregiving can lead to depression and other mental health challenges.²¹ An MPA could propose ways that family caregivers can use resources provided by the state, such as respite care, support groups, counseling, and training and education, to take better care of their own health. For example, the Centers for Medicare & Medicaid Services has given new flexibilities to enable Medicare Advantage plans to offer a wider range of supplemental benefits to address long-term services and supports (LTSS) needs including family caregiver supports (i.e., respite).²² MPAs could promote those flexibilities and encourage state agencies to get the word out to family caregivers who may qualify.



- **Offer strategies for making communities safer and more accessible.**

As previously mentioned, older adults prefer to live in their communities as long as possible, with the support of family caregivers.²³ An MPA could make it easier for family caregivers to care for loved ones in the home by elevating strategies for people to access home modifications to avoid forced relocations. Additionally, it is important that communities and neighborhoods are physically accessible. MPAs should address how the physical and social aspects of the community, such as public spaces, community centers, sidewalks, and parks, will evolve to promote accessibility and equity as older adults and their families age. For example, **California, Colorado, Florida, Maine, Massachusetts, Michigan, Minnesota, New Jersey, and New York** are all designated by AARP as *Age-Friendly States*, which means they are working on making the state accessible for older adults and people with disabilities — through creating walkable neighborhoods, bolstering transportation options, supporting housing that is affordable and adaptable, and providing opportunities to participate in community activities.²⁴



- **Include pathways for strengthening direct care workforce.**

When family caregivers need breaks, or if older adults need care and do not have family, friends, and/or neighbors to offer help, they turn to the direct care workforce. Approximately 4.7 million direct care workers (DCWs) across the country provide care for older adults and individuals with disabilities in their homes, residential care homes, nursing facilities, and hospitals.²⁵



However, the United States is facing a dire shortage of DCWs, as individuals leave the profession due to low wages, inconsistent hours, few benefits and advancement opportunities, inadequate training, and lack of value of the work.²⁶ An MPA could include strategies for strengthening the direct workforce, as they are often critical partners to family caregivers, and part of an older adult's care team.

MPAs in Action: Examples of Family Caregiving Language

Following is sample language used in MPAs in **Minnesota** and **Texas** — two states that participated in *Helping States Support Families Caring for an Aging America* initiative. Each of these states held a series of activities to engage older adults and family caregivers in their communities to inform the development of the MPA language highlighted below. For states interested in including family caregiving language in MPAs, these examples can be a helpful starting place.



Minnesota: MN 2030 Looking Forward

Minnesota Board on Aging and Health and Human Services held [community and stakeholder conversations](#) — including with family caregivers — as part of its [MN 2030 Looking Forward](#) initiative.

RECOMMENDATIONS FOR STRATEGIC PRIORITIES

- 1. Continue/increase support for caregivers of older adults during transitions of care, and others who are stressed and at risk of formal placement of older adults.** Increase partnerships with clinics, hospitals, and health care homes (HCHs), and coordination with Senior LinkAge Line[®] to identify and support family caregivers. Continue/increase support for family caregivers including those caring for adults with Alzheimer's disease, rural, low income and culturally diverse caregivers and others as per the Older Americans Act.
- 2. Increase coordination between Senior LinkAge Line[®] and caregiver services grantees to maximize support for caregivers through calls and Return to Community (RTC) Expansion.** Beginning July 2019, a new caregiving service component will be launched that offers self-directed budgets for family and friends of certain individuals enrolled in the RTC program. This is an opportunity to test new ways of supporting family and friend caregivers in a more targeted, flexible, and coordinated way.
- 3. Revamp messaging and service delivery models geared to family and friend caregivers.** Take a holistic approach of supporting caregivers and care receivers at the same time. Consider addressing the care receiver's needs first as families and friends may reach out for help during crisis or transitions of care. For example, caregivers may be more willing to take some help if it is geared towards

the care receiver (and also provides them with a break, respite). Create easy and practical service “on ramps” as initial forms of support for caregivers, including transportation, meals, chore services, or housekeeping help. Educate family and friend caregivers about LTSS options in an effort to divert/delay use of assisted living and facility-based care.

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

This also makes good business sense as supporting employee caregivers is shown to enhance productivity, lower absenteeism, improve worker retention and provides a competitive edge in recruiting high quality employees.

- 10. Establish measurable outcomes for the programs seeking to support family caregivers.** Explore methods to document return on investment for caregiver support services as a way to generate state funding in order to sustain capacity.



Texas: Aging Texas Well Strategic Plan 2022-2023

Texas surveyed older adults and family caregivers. The state is planning to convene listening sessions and broaden survey outreach to inform future iterations of the [Strategic Plan](#).

The top three concerns identified by family caregivers surveyed by the state were: (1) mental health concerns; (2) physical health concerns; and (3) work/strains and issues. Texas' MPA offers strategies to address each category of concerns:

STRATEGIES TO SUPPORT MENTAL HEALTH

- 1. Work with Aging Services Coordination (ASC) office to elevate experiences of women informal caregivers,** including impacts of caregiving on mental health and social connection.
- 2. Enhance the Alzheimer's Disease Program (ADP) website** with information for family caregivers on caregiver wellness and community resources.
- 3. Encourage intervention and treatment programs** to provide referrals on education and community support services to address mental health needs.
- 4. Increase informal caregiver access to educational resources and awareness about evidence-based programs** designed to address informal caregiver health and wellness, including stress relief.

STRATEGIES TO SUPPORT PHYSICAL HEALTH

- 1. Address the individual support system through intervention and treatment programs.** Refer people to community resources designed to address the impact of substance use on physical health needs. Provide referrals and coordinate services for specialized services.
- 2. Coordinate with the Department of Family and Protective Services, the Department of State Health Services, and external organizations** to identify resources that address the impact of untreated physical health conditions on older adults' mental health.
- 3. Continue promoting Texercise as a resource** for both older adults and their family and/or caregivers.

STRATEGIES TO SUPPORT WORK STRAINS/ISSUES

1. **Work with ASC on strategies to enhance informal caregiver support** for Medicaid beneficiaries and their families.
2. **Enhance state and local lifespan respite care systems** to provide access to direct respite services, thereby increasing the total number of informal caregivers and families served.
3. **Collaborate, support, and participate with caregiver organizations** on events, including training events.
4. **Work with organizations through the Texas Talks initiative** to elevate the experiences and issues of informal family caregivers, including impacts to employment.

Conclusion

Multisector plans for aging provide a roadmap for states to address what matters most to aging adults, people with disabilities and their families. It also elevates state initiatives, priorities and partnerships aimed at supporting older adults and people with disabilities to live in their communities. Integrating the voices of family caregivers and ensuring they play a central role in the development of the MPA is critical for creating a comprehensive plan. Family caregivers' day-to-day experiences in navigating the systems, supports, and resources necessary to support older adults makes them an invaluable partner to help shape an MPA.

An increasing number of states are recognizing the important role family caregivers can play in MPA development, as demonstrated by the examples provided in this brief. States can use a variety of strategies to engage family caregivers, including conducting surveys, holding listening sessions, and tapping community-based organizations to hear from and listen to family caregivers. As more states develop MPAs,²⁷ building in time and resources for gathering meaningful family caregiver input should be recognized as a necessary part of the process.

ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

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ENDNOTES

¹ States use a variety of names for their multisector plans for aging, including but not limited to master plan, strategic plan, and aging well plan. Regardless of the name, these plans all have the same goal to transform the coordination of services for older adults and individuals with disabilities.

² C. Graham and A. Hoffmaster. “Developing a Multisector Plan for Aging.” Center for Health Care Strategies. June 2022. Available at: <https://www.chcs.org/resource/developing-a-Multisector-plan-for-aging/>.

³ S. Simmons-Duffin. “New Federal Funds Spur Expansion of Home Care Services for the Elderly and Disabled.” NPR. October 21, 2021. Available at: <https://www.npr.org/sections/health-shots/2021/10/21/1048082143/new-federal-funds-spur-expansion-of-home-care-services-for-the-elderly-and-disab>.

⁴ National Alliance for Caregiving and AARP. “Caregiving in the U.S. 2020.” May 2020. Available at: <https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020/>.

⁵ Ibid.

⁶ S. Reinhard, L. Friss Feinberg, A. Houser, R. Choula, and M. Evans. “Valuing the Invaluable: 2019 Update. Charting a Path Forward.” AARP Public Policy Institute. November 2019. Available at: https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html?cmp=RDRCT-VALUN_JUN23_015.

⁷ National Alliance for Caregiving and AARP, op cit.

⁸ More information on *Helping States Support Families Caring for an Aging America* initiative available at: <https://www.chcs.org/project/helping-states-support-families-caring-for-an-aging-america/>.

⁹ Aging Texas Well Strategic Plan 2022-2023. Available at: <https://www.hhs.texas.gov/about/community-engagement/age-well-live-well/aging-texas-well>. Example survey questions include: (1) Indicate the caregiving challenges you've experienced over the last three years (Informal caregivers' stress was measured using a scale of 1 to 5 (1 = 'no stress' to 5 = 'extreme stress').); (2) Explain how your ability to care for an older adult was impacted by the COVID-19 pandemic.

¹⁰ Diverse Elders Coalition. “What Providers Should Know About Hispanic Family Caregivers.” May 2020. Available at: <https://diverseelders.org/wp-content/uploads/2020/10/What-Providers-Should-Know-About-HiMPAnic-Family-Caregivers-May-2020.pdf>.

¹¹ To learn more about Wisdom Steps, visit: <https://wisdomsteps.org/>.

¹² Minnesota Board on Aging. “The Minnesota Board on Aging State Plan 2019-2022.” Available at: https://mn.gov/board-on-aging/assets/State_Plan_FINAL_2019_2022_PP_tcm1141-433852.pdf.

¹³ Diverse Elders Coalition and National Alliance for Caregiving. “Family Caregiving in Diverse Communities: Addressing the Needs of Diverse Family Caregivers for Older Adults.” December 2021. Available at: <https://diverseelders.org/resource/family-caregiving-in-diverse-communities-addressing-the-needs-of-diverse-family-caregivers-for-older-adults/>. Note, the Diverse Elders Coalition offers training to health care and social service providers to help them meet these recommendations. To review training materials and all of their family caregiving resources, visit: <https://diverseelders.org/caregiving/>.

¹⁴ More information on the Indiana State Plan on Aging 2023-2026 available at: <https://www.in.gov/fssa/da/public-comments/>.

¹⁵ Kaiser Family Foundation. “Paid Leave in the U.S.” December 17, 2021. Available at: <https://www.kff.org/womens-health-policy/fact-sheet/paid-leave-in-u-s/>.

¹⁶ New York State Office for the Aging and New York State Department of Labor. “Caregivers in the Workplace: Finding Balance for Your Employees.” June 2022. Available at: <https://aging.ny.gov/help-working-caregivers>.

¹⁷ More information about Age-Inclusive Management Strategies (AIMS) is available at: <https://www.transamericainstitute.org/workplace-employers/age-friendly-workplaces>.

¹⁸ C. Roman, S. Bane, and E. Ophthof. “How Employers and States Can Support the Essential Workforce of Family Caregivers.” *American Journal of Health Promotion*. August 2021. Available at: <https://journals.sagepub.com/doi/full/10.1177/08901171211030142g>.

¹⁹ National Alliance for Caregiving and AARP, op cit.

²⁰ P. Urban. “Many Caregivers Neglect Their Own Health.” AARP. January 24, 2020. Available at: <https://www.aarp.org/caregiving/life-balance/info-2020/caregivers-health-burden.html>.

²¹ R. Chatterjee. “Unpaid Caregivers Were Already Struggling. It’s Only Gotten Worse During the Pandemic.” NPR. June 17, 2021. Available at: <https://www.npr.org/sections/health-shots/2021/06/17/1007579073/unpaid-caregivers-were-already-struggling-its-only-gotten-worse-during-the-pande>.

²² ASPE. “Comparing New Flexibilities in Medicare Advantage with Medicaid Long-Term Services and Supports: Final Report.” January 2022. Available at: <https://aspe.hhs.gov/sites/default/files/documents/03390244d012ecbbe80e81d5c972bf39/medicare-advantage-medicaid-ltss.pdf>.

²³ S. Simmons-Duffin. “New Federal Funds Spur Expansion of Home Care Services for the Elderly and Disabled.” NPR. October 21, 2021. Available at: <https://www.npr.org/sections/health-shots/2021/10/21/1048082143/new-federal-funds-spur-expansion-of-home-care-services-for-the-elderly-and-disab>.

²⁴ AARP Network of Age-Friendly States and Communities. Available at: <https://www.aarp.org/livable-communities/network-age-friendly-communities/>.

²⁵ PHI. “Direct Care Workers in the United States: Key Facts.” September 2022. Available at: <http://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>.

²⁶ C. Roman, C. Luz, C. Graham, N. Joseph, and K. McEvoy. “Direct Care Workforce Policy and Action Guide.” May 2022. Available at: <https://www.chcs.org/resource/direct-care-workforce-policy-and-action-guide/>.

²⁷ More information on the Multisector Plan for Aging Learning Collaborative available at: <https://www.chcs.org/project/Multisector-plan-for-aging-learning-collaborative/>.