



AARP CAREGIVING DATA, INSIGHT, AND RESOURCES TO INFORM REPORTING

Strengthening support for family caregivers and improving long-term care services at large are top priorities for AARP, particularly given the emotional, financial and economic toll assumed by family caregivers. Today, approximately 48 million Americans provide support to a parent, spouse or loved one. Family caregivers shoulder roughly \$600 billion worth of unpaid labor, yearly. With the population of Americans over age 65 expected to exceed that of Millennials and Gen Xers in size by 2050, finding solutions to allow people to age at home is critical to economic stability and building a healthier America.

AARP's work to elevate caregiving as a national issue includes the following:

1. Robust and sustained state-by-state legislative advocacy
2. State-by-state scorecards, published every three years, to provide a sense of which states are paving the path to progress - and which states lag behind
3. Research on long-term care, focused on family caregiving
4. Advocacy to influence executive actions, federal rulemaking and federal legislation
5. Polling on family caregiving
6. Resources and tools for family caregivers
7. Free assistance for caregivers, including a caregiving crisis hotline
8. Facebook discussion group with nearly 18,000 subscribers/ self-identified caregivers
9. Stories from people nationwide about their caregiving experience

Below are more details about these resources. We hope this snapshot serves as an evergreen guide to the latest research and insight for the months ahead.

Key AARP caregiving resources

1. Robust and sustained advocacy

- As part of its mission to support family caregivers, AARP has backed or driven dozens of new legislative proposals at the state level and successfully passed hundreds of laws – from a payroll tax credit in 42 states, to paid family leave in 14 states and the District of Columbia to provide financial relief to individuals serving as family caregivers.
- The CARE Act- now law in 45 states and territories (including DC, Puerto Rico and the Virgin Islands) –helps to ensure caregivers get the training they need to care for their loved ones following a hospital stay.
- For more resources on existing state caregiving laws and legislation that AARP is fighting for, see the separate document, “State Level Overview: Caregiving Laws & Policies Supported by AARP.”

2. State-by-state scorecards: Long-term care including family caregiving

Every three years, AARP assesses the state of long-term care service and supports in America analyzing the scope of policies in place, highlighting gaps in the system of care and providing recommendations to better support family caregivers, direct care workers and those receiving care. See AARP’s latest [scorecard](#) published September 2023.

3. Research on long-term care, focused on family caregiving

To inform its advocacy work, AARP relies on in-house research and analysis to understand the tools and resources family caregivers need – and the policies that states and the federal government could pass to improve quality of life for family caregivers, direct care workers, and those receiving care. AARP’s latest research includes:

- [Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers](#)
- AARP Policy Now Video: [Valuing the Invaluable](#)
- [Family Caregiver Considerations for the Future of Hospital at Home Programs](#)
- AARP Policy Now Video: [Recognizing the Role of Family Caregivers in Hospital at Home](#)
- [Caregiving Out-of-Pocket Costs Study](#)
- [Caregiving in the US 2020](#)
- [Home Alone Revisited: Family Caregivers Providing Complex Care](#)
- [LTSS Choices: Empowered Direct Care Worker: Lessons from the Green House Staffing Model](#)
- [LTSS Choices: Home and Community-Based Services for Older Adults](#)
- [LTSS Choices: National Inventory of Self-Directed Long-Term Services and Supports Programs](#)
- [LTSS Choices: Addressing Racial and Ethnic Disparities in Nursing Homes](#)
- [LTSS Choices: Respite Services: A Critical Support for Family Caregivers](#)
- [LTSS Choices: Addressing the Gap: Exploring Disparities in Long-Term Services and Supports](#)
- [LTSS Choices: Nursing Home Workforce Issues and Inequities](#)

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4. Advocacy to influence executive actions, federal rulemaking and federal legislation

AARP's Chief Advocacy Officer and Executive Vice President Nancy LeMond spearheads our work to ensure caregiving is not an afterthought in legislation or rulemaking from agencies, such as the Health and Human Services Department, but a focus.

- The April 2023 [Executive Order](#) to support family caregivers, early childhood educators and long-term care workers includes key priorities that AARP has advocated for, including discharge planning; hospital at home; access to Medicare information for family caregivers; and a demonstration that includes support for family caregivers.
- For information on AARP's position on recent proposed rules or legislation to address family caregiving needs, visit [AARP's Government Watch page](#). For example:
 - [Centers for Medicare & Medicaid Services' Medicare Physician Fee Schedule](#) proposed a policy for 2024 to pay for family caregiving training services. Making caregiver training services available through Medicare is important to ensure access to these critical services for caregivers who need them. AARP advocated in support of this provision. CMS finalized this proposal in November 2023, and it went into effect in [January 2024](#).
 - For more examples of rulemaking in recent years and AARP's vision for the future, please see document titled "Caregiving Rulemaking and Other Administrative Actions at a Glance."

5. Polling on family caregiving

In 2023, [AARP surveyed registered U.S. voters](#) and found that nearly 40 percent of family caregivers spend more than 20 hours a week assisting with everything from driving a family member or friend to appointments to managing medical claims to providing hands-on assistance, while many of them hold down full or part-time jobs and care for children. Caregiving and how it shapes voter attitudes about health and the economy will continue to be a priority issue for AARP, with the goal of getting political candidates to start paying more attention to what could be an issue for swing voters in competitive Congressional districts.

- Latest caregiving poll, "[U.S. Voters' Views on Support for Family Caregiving](#)" May 2023
- See also our [July 2023 survey of likely 2024 voters](#), which shows that 77 percent of likely voters either are current caregivers, have been a caregiver or expect to be one in the future. And nearly 80 percent of current caregivers say they plan to vote in the 2024 election.

6. Resources and tools for family caregivers

[AARP.org/caregiving](#) serves as an online hub for resources available in English and Spanish to family caregivers and the latest "how to" articles from AARP writers with expertise in the latest caregiving issues and trends.

Some headlines, for example:

- Tools to Care for an Older Adult
- 10 Tips for Splitting Caregiving Costs Among Siblings



[Please also see AARP's Family Caregiving How-To Video Series](#)

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7. AARP's help resource line

Anyone facing a family caregiving crisis can call **AARP's hotline, 877-333-5885**, and seek help in English or Spanish. AARP agents who run the help line offer resources, including the following:

- Care for the caregiver
- Home care
- Long-term care
- Caregiving work
- Legal issues
- Medical care
- Financial issues
- Long-distance caregiving
- Veteran caregiving

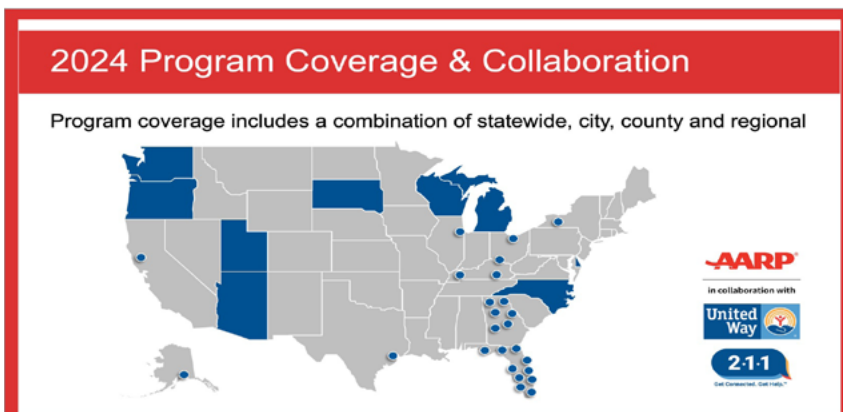
8. The 211 Caregiver Support Program

In 2021, AARP and United Way Worldwide came together to help caregivers access local and federal resources through the 211 Caregiver Support Program. Now, caregivers in need can call 211 for help getting matched with critical resources to:

- Address basic necessities, such as housing, food, and employment that take the focus off of caregiving.
- Connect to community services and organizations, with guidance from someone who knows the community.
- Simplify access to specialized help while anticipating changes in care situations in tandem with the caregiver.

By simply dialing 2-1-1, caregivers can get the answers they desperately seek. We view this initiative as a one-stop shop for finding essential services, including health care, food, and emergency financial aid.

211 is free to use and is delivered by over 220 local organizations across the country. 211 is available to over 99% of the US Population. Enhanced caregiver support is available in a quarter of the country and growing. There are nearly 50 call center sites nationwide right now and, in the year ahead, AARP plans to work to expand that number by the dozens.



To learn more, please visit: www.aarp.org/211care.

9. AARP's Facebook caregiving discussion group

Amy Goyer, a leading national expert on family caregiving, moderates the [AARP Family Caregivers Discussion Group](#) on Facebook, providing a real-time look at the trials faced by countless caregivers across the country. While this is a private group with tens of thousands of members and growing, you can seek membership online by identifying yourself and news outlet and stating your connection or interest to family caregiving as an emerging issue.

- To reach out to anyone posting messages in the group once you are admitted, please contact media@aarp.org.
- While Facebook group members may be open to sharing their stories for news purposes, they have not consented to being approached without hearing from AARP first.

10. Collecting stories from individuals nationwide

Daphne from Virginia and Daniel from Massachusetts are just two examples of people with heart-wrenching caregiving stories to tell. Daphne from Virginia is a caregiver for her 86-year-old bed-bound mother. She is emotionally drained, and her mother's medical bills are never ending, but she and sisters want to continue caring for her. Daniel from Massachusetts is also a caregiver for his mother, who suffers from significant health issues and is at risk of falling. Daniel is unable to work because his mother requires 24/7 care. Contact media@aarp.org to connect with Daphne, Daniel, and other family caregivers across the country to hear their stories.

For inquiries, contact: media@aarp.org

Learn more: aarp.org/caregiving