



STATE LEVEL OVERVIEW: CAREGIVING LAWS & POLICIES SUPPORTED BY AARP

AARP has a 60+ year history of advocating for older adults, empowering them to choose how they live as they age and fighting for policies that allow them to age in their own homes and communities where we know through our research they would like to be. Recognizing that family caregivers are critical to aging in place, AARP accelerated our advocacy work on behalf of family caregivers in 2014 with the CARE Act - now law in **45 states**. Building on the foundation of the CARE Act, AARP state offices around the country have led the charge in bringing real, tangible relief to our nation's 48 million family caregivers – passing state legislation that supports family caregivers in 44 states and 3 territories.

With 77% of registered voters being a current, past, or future **family caregiver**, AARP's advocacy work on behalf of family caregivers cuts across political ideologies. And with 21% of registered voters identifying as a current family caregiver, elected officials and candidates would do well to consider the needs of this growing political constituency.

State caregiving advocacy – the why

Caregiving By the Numbers

- Number of Caregivers: **48 million**.
- Between now and 2050, the number of Americans **85** and older will increase **200%** and those between **75** and **84** will increase **100%**.
- Of the **48 million** family caregivers, **11.2 million** are caring for somebody living with dementia, and that number is expected to triple by 2050.

Financial Impact

- Estimated economic value of family caregivers' unpaid contributions: **\$600 billion**.
- On average, caregivers are spending more than **\$7,200/year out-of-pocket**, which for many accounts for one-quarter or more of their annual income.
- **78%** of caregivers incur routine out-of-pocket costs.
- **47%** have experienced at least one financial setback as a result of their caregiving.
- On average, caregivers spend a quarter of their annual income on caregiving expenses.

Impending Crisis (Caregiver shortage)

- By 2034, **adults ages 65 and older will outnumber children under 18**, and the share of potential caregivers is projected to continue shrinking relative to the number of older adults potentially at risk for needing long-term care.
- Direct care workforce shortages, exacerbated during the pandemic, result in more hours of care and higher intensity care by family caregivers. While the workforce is expected to grow from **4.6 million in 2019 to 5.9 million by 2028**, the challenge is in retaining workers in a field with an average turnover rate of **40 to 60%** each year and providing sufficient pay and training.

State caregiving advocacy – the who

Women

- **61%** of family caregivers are women and women devote 50% more time to caregiving duties than men.
- **One in three** women caregivers pass up promotions, training opportunities and new assignments in the workplace.
- In December of 2021, women had lost nearly **60% of the 3.6 million jobs** that vanished as a result of the pandemic.

Millennials

- **47%** of family caregivers are under the age of 50, including about a quarter who are Millennials.
- Roughly **30%** of family caregivers live in a household that also includes children or grandchildren. Known as the “sandwich generation” these are increasingly Millennial caregivers and are more likely to be working full or part-time.

Caregivers of color

- **Over 30%** of family caregivers self-identify as a racial or ethnic minority.
- Caregiving can have disproportionate impacts on people of color and these groups face unique challenges in accessing and utilizing our healthcare system.

Caregiving policy principles

The three principles listed below, which map to the [National Strategy on Family Caregiving](#) released in September 2022, outline the overarching areas AARP believes policymakers at the state and federal levels can focus on to better address the growing needs – and preserve and improve the general health and well-being – of our nation’s unpaid family caregivers.

Make providing care – and finding paid care – easier for family caregivers

New and existing family caregivers alike often find the long-term care system challenging to navigate. Policymakers should make finding and providing care easier for family caregivers and better incorporate and recognize family caregivers and their vital role as a part of the nation’s long-term care team.

Related policies: HCBS expansion, navigation, direct care workforce, education/training.

Alleviate the economic, financial, and other challenges directly associated with caregiving responsibilities

Family caregivers face a variety of emotional, physical, and financial challenges that can not only result in poor outcomes for those they are assisting but can also have long-term effects on family caregivers themselves. Policymakers should look to alleviate some of these challenges by expanding services and resources available to family caregivers.

Related policies: Paid leave, sick leave, caregiver compensation/self-direction, tax credits/reimbursement programs, financial and legal protections.

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Increase and ensure access to services and supports for all family caregivers

Addressing racial, economic, and health disparities and the distinct needs of underserved communities is crucial to supporting America's family caregivers. When crafting and implementing policy solutions, policymakers should ensure their proposals are addressing the wide spectrum of experiences and needs that family caregivers face and that those proposals are not adding to existing disparities.

Related policies: respite care, caregiver assessments.

Related considerations when developing policy to support family caregivers: geographic, racial, economic, ethnic, language, ability/mobility, and other barriers.

State Advocacy

MAKE PROVIDING CARE — AND FINDING PAID CARE — EASIER FOR FAMILY CAREGIVERS

Home and Community-based Services

- AARP fights to keep people in their homes and communities and out of costly institutions, including fighting to ensure that it is just as easy for individuals to receive care at home as it is to get them into a nursing home after being discharged from the hospital.
- AARP also fights for respite care and other services, such as help with housekeeping, that support family caregivers and make it possible for them to care for their loved ones at home.

CARE Act

- The Caregiver Advise, Record, Enable (CARE) Act – AARP's model legislation – is now law in 45 states and territories (including DC, Puerto Rico and the Virgin Islands). Oklahoma was the first state to pass the CARE Act in 2014 and Georgia the most recent in 2022.
- The CARE Act was intentionally designed as budget-neutral legislation that would start building momentum for more robust change.
- The laws help to ensure caregivers get the training they need to care for their loved ones following a hospital stay.

ALLEVIATE THE ECONOMIC, FINANCIAL, AND OTHER CHALLENGES DIRECTLY ASSOCIATED WITH CAREGIVING RESPONSIBILITIES

Paid Leave

- AARP has been instrumental in passing laws to create and expand paid leave policies that directly benefit family caregivers. AARP has helped pass paid family leave in 13 states and the District of Columbia. These states include: California, Colorado, Connecticut, Delaware, Maine, Maryland, Massachusetts, New Jersey, New York, Oregon, Rhode Island, and Washington.

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- A total of 15 states (Arizona, California, Colorado, Connecticut, Maryland, Massachusetts, Michigan, Minnesota, New Jersey, New Mexico, New York, Oregon, Rhode Island, Vermont, Washington) and the District of Columbia now require paid sick leave and an additional three (Nevada, Maine, and Illinois) have enacted general paid time off laws that allow for paid sick leave (18 total).
- With 3 out of 5 caregivers balancing work with their caregiving responsibilities, these paid leave policies help to ensure that working caregivers can maintain their jobs and their incomes while providing care for their loved ones.

Financial Support

- On average, caregivers spend over **\$7,200 per year out-of-pocket** on caregiving responsibilities. These policies reduce the financial challenges for caregivers and recognize the critical role caregivers play in reducing the need for taxpayer-funded care.
- AARP offices across the country also advocate for policies that provide financial relief for family caregivers in the form of stipends, tax credits, or compensation.
- AARP has worked with several states, including Maine, Arizona, Oklahoma, and New Jersey, to offer tax credits or other reimbursement programs for family caregivers who incur expenses while caring for their loved ones.
- AARP has also fought in a number of states to ensure that family caregivers who have had to leave the workforce to care for a loved one can be reimbursed for providing that care.
- All 50 states and Washington DC have at least one self-directed care program, which allows individuals receiving services in their homes and communities to receive a monthly allowance that may be used to hire, supervise, train, schedule, manage, and fire their own workers.
- Most states have some restrictions on which designated representatives or family members can be hired as paid service providers. However, AARP has been working to urge states to allow individuals self-directing their care to hire and pay family members for their caregiving. For example:

In 2023, AARP Utah supported a law requiring the Department of Health and Human Services to apply for a federal Medicaid Waiver amendment to implement a program to reimburse a parent or guardian who provides extraordinary personal care services to a waiver enrollee.

AARP Maine was similarly engaged in the recent passage of a law requiring an existing 1915(c) waiver to be amended to enhance participant direction.

INCREASE AND ENSURE ACCESS TO SERVICES AND SUPPORTS FOR ALL FAMILY CAREGIVERS

Respite

Respite is temporary care that is provided to an older adult or person with a disability so their family caregiver can take a short break, rest, and tend to their own needs. According to the 2020 [“Caregiving in the U.S.”](#) report from AARP and the National Alliance for Caregiving, 38 percent of caregivers said they felt respite would help them, but only 14 percent receive respite. Respite care can be for a couple of hours or a few weeks, and it can take place either at a private home or a community setting such as an adult day care center.

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AARP supports policies that: preserve and expand funding for respite care services in a range of settings, preserve and expand funding for respite care whether someone is eligible for a publicly funded program (such as Medicaid) or pays privately for services, and allows family caregivers who are assisting individuals with moderate incomes to access services even if they do not qualify for publicly funded respite services.

AARP Maine advocated for the creation of the Respite for ME: Family Caregiver Grants Pilot Program in 2022. This program, which was created with the American Rescue Plan (ARPA) funding, gives eligible caregivers grants of up to \$2,000 to access respite care and other support services.

In order to be eligible for the program, caregivers must be: caring for a family member who is 60+ or living with dementia; a relative (other than a parent) age 55+ who cares for children under age 18; or a relative age 55+ who cares for an adult age 18 – 59 with disabilities. Caregivers must also be able to demonstrate that they were negatively impacted or suffered economic hardship due to the COVID-19 pandemic.

Caregiver Assessments

Caregiver assessments explore the needs, problems, strengths, and resources of the family caregiver by asking the caregiver directly, as well as their ability to contribute to the needs of the person they are assisting. This allows for more efficient and effective targeting of caregiver support based on the assessment. It helps ensure the family caregiver receives the support most helpful to them and their individual needs and caregiving situation.

AARP recognizes that it's just as important to provide care for the caregiver as it is for the care recipient and has advocated for comprehensive caregiver assessments so that caregivers get the support they need to care for their loved ones.

Guardianship

AARP advocates at the state level to assist caregivers in accessing the legal tools to care for their loved ones while also protecting vulnerable seniors who rely on legal guardians for decision making.

For much of the country, guardianship laws are out of date. Most states haven't had a major revision of their guardianship laws in over 20 years. Sixteen states haven't had a revision in three or more decades.

The Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA) was approved by the Uniform Law Commission in July 2017 and AARP was involved in its drafting. To date, the act has been enacted in its entirety in Maine and Washington, and partially in Iowa, Nevada, New Mexico, Mississippi, and South Carolina.

Currently, guardianship information, rules, and forms can vary from county to county, state to state, and even court to court.

State offices advocate for guardianship standards that are more consistent as well as standards that help protect vulnerable seniors from "bad actors" who aren't acting in the best interests of the seniors who rely on them.

For inquiries, contact: media@aarp.org

Learn more: aarp.org/caregiving