Supporting America's
53 Million Family Caregivers

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Background

The vast majority of Americans with long-term care needs wish to remain in their homes and access services either at home or in their communities, rather than in nursing homes or other forms of institutional care.[1] To support people in living at home or the community as they age, the long-term services and supports (LTSS) system relies heavily on the support of unpaid family caregivers. Family caregivers are defined by the Administration for Community Living (ACL) as "all who are caring for individuals across the lifespan with chronic or other health conditions, disabilities, or functional limitations," and is broadly interpreted to include "spouses, partners, children, siblings, friends, neighbors, kin, cousins, nieces and nephews, grandparents, parents, godparents, and others."[2] States may employ more narrow definitions.[3] According to the American Association of Retired Persons (AARP), a caregiver is someone who provides unpaid care to a loved one who has a chronic or disabling condition – approximately 53 million Americans meet this definition.[4]

Regardless of definition, demographic changes including an aging population, lower birth rates, greater workforce participation among women, and shifting immigration rates will have significant effects on the future of family caregiving in America.[5] As Medicaid is the primary payer for the LTSS that help older adults and people with disabilities live their lives independently, unpaid family caregivers will be an increasingly crucial component of efforts to control healthcare costs while providing quality care. There is strong bipartisan support for caregiver initiatives among the electorate, and voters rank caregiving issues as highly important. Polling has found that 70 percent of voters aged 50 and older are more likely to support a candidate who backs proposals to support family caregivers, such as tax credits, paid family leave and respite services.[6]

This policy brief provides an overview of the family caregiver experience, available options and funding mechanisms for caregiver support, and steps policymakers and healthcare professionals can take to support this critical population.

Caregiver Contributions

Tens of millions of Americans take on the role of unpaid caregivers, often without consciously identifying themselves as such.[7] These individuals provide essential support to loved ones, with 61% juggling caregiving responsibilities alongside full- or part-time employment.[8] Unpaid caregivers fulfill roughly 80% of the needs for older adults and individuals with disabilities. Without these unpaid caregivers, both the LTSS system and larger healthcare system would cease to function.[9]

For many, caregiving is a deeply rewarding experience, offering opportunities to connect and care for loved ones in meaningful ways. However, about one-third of caregivers also find the role to be a source of significant stress.[10] Contrary to common belief, only about 3% of older Americans require nursing home care, a percentage that was declining before the COVID-19 pandemic and which continues to decline. The United States remains, in essence, a country in which families take care of their loved ones.[11]

Caregiving labor often takes the form of "sweat equity" – running errands, performing housework, or assisting with home repairs rather than direct personal care, such as feeding, bathing, or dressing. A significant aspect of caregiving is also emotional support, which is often overlooked but invaluable in nurturing the well-being of those in need.

Physical, Emotional, and Financial Tolls

Intensive or complex caregiving (for example, caring for a relative with a physical disability and co-morbid dementia, or an aging adult with an intellectual or developmental disability [I/DD]) can be overwhelming and can create significant physical, mental, emotional, and financial burdens for caregivers. These burdens on caregivers are associated with adverse health outcomes for the people they take care of and subsequently contribute to higher costs for states.

Women bear a disproportionate share of this burden, outnumbering male caregivers three to one and dedicating 50% more time to caregiving responsibilities. However, caregiving is not a uniform experience; it varies widely based on region, income, race, ethnicity, gender, sexual orientation, and other demographic factors.[12]

Caregiver stress is associated with significant health risks, including cardiovascular disease, depression, and social isolation, and it also impacts care recipients by contributing to poorer health outcomes. [13]

These outcomes may include prolonged hospitalization, cognitive and functional decline, and increased risk of institutionalization.[14] Furthermore, caregiver stress is a major risk factor for elder abuse, highlighting the critical need for adequate support systems.[15]

The challenges faced by caregivers were further exacerbated by the COVID-19 pandemic, which profoundly affected older adults, people with disabilities, and their caregivers. The physical and psychological impacts of the pandemic continue to unfold, adding to the already significant burdens on caregivers.[16]

Nearly 80% of caregivers regularly incur out-of-pocket expenses while caring for loved ones.[17] On average, these expenditures amount to over $7,200 per year per caregiver, further straining personal resources.[18] The total economic value of unpaid caregiving has been estimated at over $600 billion annually, an increase of $130 billion compared to pre-pandemic estimates and far exceeding the value of paid home care.[19]

Supporting Caregivers

A growing body of evidence demonstrates that policies that strengthen supports for family caregivers can ease these burdens and help caregivers be more effective for their loved ones.[20] [21] Better supports for unpaid caregivers reduce hospital admissions, shorten hospital stays, reduce or delay the need for more complex services, delay or prevent institutionalization, and reduce strain on the paid workforce during an ongoing nationwide workforce crisis, all of which relieve pressure on the healthcare system and therefore on state budgets.

Research demonstrates that caregivers benefit from additional supports that help with:

- Reducing isolation and loneliness and preventing physical and mental burnout through respite options, including in-home and adult day programs [22]
- Relieving financial burdens through caregiver payments, tax credits, and workplace flexibilities [23]
- Building caregiver self-identification, confidence, and skills through awareness, training, education, and oversight [24]
- Easing the emotional burdens of caregiving through supportive counseling [25]

Many caregivers only seek out services during or after a care crisis. Policies and interventions that support caregivers earlier in the caregiving process reduce long-term costs to healthcare budgets. This means that costs associated with additional caregiver supports can potentially be lowered if caregivers are supported in their mental and physical health and have access to quality training and resources.[26] Policymakers should take this into consideration when developing new policies and programs.

Types of Direct Supports

A variety of supports that enhance caregiver health and wellbeing can be implemented by governments and other public entities, as well as by private employers.

Respite is a temporary break from caregiving responsibilities, allowing caregivers to rest and recharge while ensuring their loved ones continue to receive care. Respite can be provided in various settings, including in-home care, adult day programs, or short-term stays in residential facilities. Respite can help prevent caregiver burnout, reduce stress, and improve overall well-being. It also enhances the health of care recipients by ensuring they are cared for by a well-rested and more resilient caregiver.

Financial supports for caregivers can include direct payments, tax benefits, and subsidies for caregiving related expenses. Caregivers who receive financial support, such as tax credits and stipends, are more likely to stay employed, reducing long-term financial hardship.

Supports for working caregivers can include paid family leave, flexible work schedules and settings, and access to employee assistance programs (EAP). Such supports allow caregivers to remain employed while continuing to provide care without severe economic hardship.

Skills training that provides essential skills in personal care, mobility assistance, medication management, and emergency response can equip caregivers with the knowledge and confidence to provide effective care. Training can also include strategies to reduce stress, prevent burnout, and improve communication with other members of an individual's care team.

Supportive counseling, whether peer-to-peer or under professional guidance, can help caregivers manage stress, improve skills, and navigate the challenges of caregiving. Providing these services in virtual settings allows caregivers more freedom and flexibility.

A National Strategy to Support Family Caregivers

In recognition of the urgency of addressing the needs of caregivers, a national effort to support family caregivers is currently underway.

In 2016, the National Academies of Sciences, Engineering, and Medicine published Families Caring for an Aging America, which gives a thorough overview of the challenges facing American family caregivers and contains recommendations for vigorous public and private sector policies to support them.[27] After the publication of the report and lobbying by a diverse coalition of advocacy groups, two pieces of bipartisan legislation – the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act and the Supporting Grandparents Raising Grandchildren (SGRG) Act – were signed into law in 2018. From the respective pieces of legislation, two advisory councils were formed in 2019 to explore and document challenges faced by caregivers, provide actionable recommendations for supporting those caregivers, and direct the development of a national family caregiving strategy. *The National Strategy to Support Family Caregivers* (Strategy) was delivered to Congress in 2022 and identifies five overarching goals that all entities should aim for when crafting policies and programs: (1) Increase awareness of and outreach to family caregiver; (2) Advance partnerships and engagement; (3) Strengthen services and supports; (4) Ensure financial and workplace security; and (5) Expand data, research, and evidence-based practices. To help implement the goals of the Strategy, ACL has awarded multiple multiyear grants.

Building Awareness and Increasing Self-Identification

Caregiver awareness campaigns play a crucial role in educating the public about the importance of caregiving while providing much-needed support and recognition for caregivers. These campaigns can be launched at any level – public or private – and help reduce isolation by connecting caregivers with support networks, encouraging the use of available resources such as respite care and financial aid, and advocating for policy changes that benefit caregivers. Additionally, raising public awareness fosters a more compassionate society, helping employers, family members, and communities understand the challenges caregivers face and how they can offer meaningful assistance. By increasing recognition and support, these campaigns ultimately contribute to improved caregiver well-being and more sustainable caregiving practices.

A key goal of these awareness efforts is increasing self-identification among caregivers, as many individuals provide care to loved ones without realizing they are, in fact, caregivers. Recognizing this role is essential because it encourages individuals to seek help, access vital resources, and practice self-care, reducing the risk of burnout.[28] Self-identification also strengthens advocacy efforts, ensuring more voices are heard in pushing for better caregiver policies and support systems. Furthermore, caregivers who embrace their role tend to be more proactive in managing their health and well-being, which in turn allows them to provide higher-quality care to those who depend on them. By fostering self-awareness, these campaigns empower caregivers to navigate their responsibilities with greater confidence and access the support they need.

Increasing Access to Respite

Respite is crucial for preventing caregiver burnout, reducing stress, and improving caregiver and recipient well-being. To expand respite options, policymakers can increase funding for Medicaid waiver programs that cover respite services, create tax incentives for families using respite care, support the development of more respite care facilities and programs, and strengthen workplace policies to allow employees to take paid caregiving leave. Expanding access to respite care ensures that caregivers can maintain their physical and mental health while continuing to provide high-quality support to their loved ones.

In 2006, Congress authorized the *Lifespan Respite Care Program* – competitive grants intended to offer coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with disabilities. These programs are intended to reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels. Respite programs are also associated with budgetary benefits – periodic respite is far less costly than full-time assisted living or nursing home care. However, limited appropriations reduce the program's impact. Since 2009, 39 statewide respite programs have been funded.[29] The Lifespan Respite Resource Center helps respite programs enhance and sustain their work.

Strengthening the Direct Care Workforce

Paid caregivers who work in caregiving professionally are known as direct care workers. They include licensed or certified nursing assistants (CNAs), direct support professionals (DSPs – those working primarily with individuals with intellectual and/or developmental disabilities), personal care attendants, home health aides, and others. Nearly five million direct care workers provide care to an estimated 10 million Americans at home and in the community, as well as in residential and nursing facilities. An unknown number of workers operate in the gray market, meaning they are hired privately by families who can afford to pay out-of-pocket. America continues to grapple with a nationwide direct service workforce shortage emergency that intersects with all aspects of family caregiving. Family caregiver well-being is inextricably linked to the improvement of conditions, pay, and career pathways for paid caregivers. Policies and programs that strengthen and support direct care workers strengthen and support family caregivers, and vice versa. For example, strengthening respite options for family caregivers may involve improving pay for respite providers. Pressure on the direct care workforce can also be eased through the adoption and promotion of self-directed care models.

Another way to support both family caregivers and direct care workers while promoting person-centered care for individuals with LTSS needs is through self-direction, also known as consumer-directed care. Self-direction allows individuals with LTSS needs to manage their own care, including choosing their caregivers, managing budgets, and determining how services are delivered to best meet their needs. Self-direction can ease the pressure on the workforce by allowing individuals to hire family members, friends, neighbors, or other trusted caregivers.

Promoting Financial and Workplace Stability

The number of people providing caregiving is increasing and is predicted to continue to grow over the next decade.[30] Supporting the financial stability of family caregivers is essential, as many face significant economic challenges while providing unpaid care to loved ones and are at a 26% higher risk of financial insecurity than non-caregivers. Women, who make up over 60% of caregivers, are particularly vulnerable to long-term economic consequences, including reduced lifetime earnings and lower retirement savings. Without financial support such as tax credits, stipends, or direct compensation for caregiving, many caregivers struggle to meet their own financial needs, increasing their risk of poverty and economic instability. More states are offering caregiver payments and tax credits, and there is political appetite for legislation that would provide a tax credit at the federal level.[31]

> Most family caregivers are employed, with more than 70% working 30 hours or more per week in addition to their caregiving responsibilities.

More than 60% of working caregivers experience at least one change in their employment due to caregiving (reduced work hours, taking leave of absence, performance/attendance warnings). The economic effects of turnover, absenteeism, and presenteeism (workers unable to fully perform their duties) due to family caregiving is significant.[32] Supports for working caregivers such as paid family leave, disability insurance, and anti-discrimination statutes offer some protection.

Employers that take the initiative in supporting their employees with caregiving responsibilities can reap benefits.

A 2021 AARP analysis found that employer supports for working caregivers aged 50 and older contribute to increased productivity, enhanced loyalty, support recruitment and retention and even increase company share prices.[33] Examples of such supports include:

- Performing a self-assessment for status as caregiver-friendly employers
- Fostering a culture of caregiver awareness
- Implementing mentorship programs
- Providing workplace flexibilities (e.g., telecommuting, flex time, paid family leave)
- Offering off-cycle payroll
- Offering in-house stress reduction programs
- Implementing an Employee Assistance Program (EAP)
- Offering access to legal and financial counseling

States are engaging in partnerships to create programs and resources for employers wishing to better support working caregivers. Massachusetts has partnered with employers and universities to increase awareness of caregiving issues. The initiative compiled a Cost of Caregiving Report quantifying the cost of increased turnover, absenteeism, and presenteeism to employers in Massachusetts – an estimated $2.1 billion per year.[34] Minnesota published a Resource Guide for Employers to implement evidence-based supportive policies that benefit caregivers, care recipients, employers, and the state.[35] New York launched a campaign to raise caregiver awareness and self-identification by targeting working caregivers.[36]

How Healthcare Professionals Can Support Caregivers

A substantial percentage of spouses of Medicare enrollees (as high as 74%) receive information about caregiving supportive services from a medical provider or social worker. [37]

Family caregiver health and well-being is a critical non-medical health factor for individuals receiving care. Because health professionals are one of the primary channels through which caregivers receive information, it is important to know how to support caregivers. The following are some suggested actions healthcare providers can take.

Make caregiver awareness training available for health professionals. Giving healthcare professionals the confidence and skills to identify, engage, and support caregivers is essential. Identification of caregivers and knowledge of available services can lead to improved patient experience, as well as help avoid duplication of service, as certain populations, such as veterans, have caregiver benefits that can be accessed. *Recently developed training* by the University of California, San Francisco, is offered free of cost, with the option of claiming continuing education units.

Integrate family members into care teams. Care team integration involves including family members as part of an individual's interdisciplinary care team, alongside doctors, nurses, rehabilitative therapists, social workers, pharmacists, care managers, and other professionals. Family caregivers offer valuable insight into the individual's preferences, routines, history, and current health status. Their involvement enhances care planning and assessment, improves care coordination and medication management, strengthens monitoring and reporting of health changes, and contributes to better care quality, outcomes, and efficiency, while also helping to reduce healthcare costs. The use of patient portals, caregiver apps, and/or support liaisons can be useful tools for communication and coordination. Care team integration is especially important during the patient discharge and other care setting transitions. Successful transitional care models like the *Bridge Model*, *AIMS* (Ambulatory Integration of the Medical and Social) and the *CHaSCI* care model, developed at Rush University Medical Center in Chicago, leverage social workers, community health workers, and others to coordinate with older adults and adults with complex medical and social needs and their caregivers as they go home from a stay at the hospital or a skilled rehabilitation facility.

Perform self-assessment as a caregiver-friendly workplace. As described in the section on financial and workplace stability, promoting caregiver awareness as an employer can improve workplace culture, employee retention, and overall productivity. One of the first steps employers can take is conducting a self-assessment. After performing an assessment, employers can discern what, if any, caregiver supports are needed and feasible.

Provide billing guidance. Changes to the Medicare Physician Fee Schedule in 2024 allow for reimbursement for caregiver training and education. Time spent during routine visits, Initial and Subsequent Annual Wellness Visits (AWV), Health Risk Assessments, and follow-up visits may be billable. *Federal billing guidance* is now available.

How Caregivers Access Services

The primary means through which caregivers access services and supports are Medicaid, Older Americans Act (OAA) programs, the U.S. Department of Veterans Affairs (VA), and state-funded programs. Accessing supports through these programs is constrained by eligibility (e.g. age, income, service status) and limited funding. Often a surprise to new recipients, Medicare offers only limited caregiver supports. Only a small percentage of family caregivers in America are receiving support through public programs.[38] In the private sector, caregiver supports are found through employers, health insurance plans, and community-based organizations. Families can also pay out-of-pocket for services such as respite and coaching. Services and supports for family caregivers in the United States, whether public or private, are largely underutilized and underfunded.[39]

MEDICAID

Medicaid is the primary payer for LTSS for older adults and people with disabilities. Most services offered by Medicaid target the care recipient, not the caregiver. However, there is increased awareness of the value of supporting caregivers. While Medicaid benefits focus on recipients, states can use waivers to provide caregiver supports like respite, training, and counseling. States have flexibility in tailoring Medicaid services through waivers, enabling expanded services and self-directed care. Indiana, for instance, now offers Caregiver Coaching and Behavior Management, which offers structured assessments and expert-led coaching and training for caregivers. Some states, through 1115 waivers, offer supports directly tailored to caregivers. The number of states with such supports is expanding.[40] While Medicaid benefits are limited to eligible recipients, states like Washington do not require caregivers themselves to be Medicaid-eligible to receive caregiver supports under their 1115 waiver programs. Additionally, all 50 states and the District of Columbia offer *self-directed LTSS*. Self-direction, also known as participant or consumer-directed care, enables older adults and individuals with disabilities or chronic conditions on Medicaid to make their own decisions about how, when, and from whom they receive services and supports. This approach offers greater choice, control, and flexibility compared to traditional care models, allowing participants to manage their own care providers (employer authority), budgets (budget authority), or both. Participants often are able to hire their own family members as care providers, reducing financial burdens while promoting caregiver and care recipient health and wellbeing. Structured Family Caregiving (SFC), an alternative Medicaid model for individuals that may not be suitable to self-direct, such as person with Alzheimer's disease and other dementias, is also gaining popularity with states. This model provides a stipend for live-in caregivers, as well as caregiver coaching support.[41]

MANAGED CARE

Managed Care Organizations (MCOs) contract with states to provide LTSS and can provide respite and training as part of person-centered care plans. Additionally, MCO contracts can be leveraged by states to require caregiver assessments, identification and inclusion of family in care coordination per recipient preference, options counseling, 24/7 nurse support lines, and case management services. Managed Long-Term Services and Supports (MLTSS) is a specialized Medicaid service delivery model where MCOs are given a set capitation payment per member per month and are incentivized to support recipients' health in innovative and cost-effective ways, including through caregiver supports. MLTSS is available in 26 states as of 2025.[42]

MEDICARE

Direct supports for caregivers through Medicare are limited. Many caregivers are surprised to learn that not only does Medicare not cover caregiver supports, but access to Medicare home health for individuals is also very limited.[43] Medicare Advantage plans, however, are increasingly offering caregiver supports as supplemental benefits.[44] As mentioned previously, certain services are now eligible for Medicare billing. Additionally, the recently launched *GUIDE (Guiding an Improved Dementia Experience) Model* is supporting family caregivers of people living with dementia by providing a comprehensive Medicare package that includes care navigation, training, respite, and emotional support. The GUIDE Model is intended to help reduce caregiver stress, improve care coordination, and empower families to manage dementia care more effectively at home.

OLDER AMERICANS ACT

The Older Americans Act (OAA) provides funding for *National Family Caregiver Support Programs* (NFCSP) in every state through Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs). Unlike Medicaid, OAA programs do not have income requirements for eligibility, though services are targeted to those in greatest social and economic need. The NFCSP has three eligibility categories, which are: 1) adult family members or other caregivers 18 and older providing care to an individual 60 and older or any age with Alzheimer's disease; 2) older relatives (non-parents) age 55 and older providing care to children under 18; and 3) older relatives, including parents, age 55 and older providing care to adults aged 18-59 with disabilities.[45] Approximately 740,000 caregivers received NFCSP services annually, which include respite, information and referral, counseling and training, and supplemental services.

VETERANS' CAREGIVING BENEFITS

Learning to identify and engage the more than 16 million veterans and their families in healthcare settings is vital. The U.S. Department of Veterans Affairs (VA) offers two caregiver support programs, the Program of General Caregiver Support Services (PGCSS) and the Program of Comprehensive Assistance for Family Caregivers (PCAFC). PGCSS serves as the core VA caregiver program, providing peer support, training, coaching, telephone support, and referrals to other services. To be eligible, the veteran must be enrolled in VA health care and require assistance with at least one activity of daily living (ADL). Caregivers for PGCSS do not need to be a relative or live with the veteran. PCAFC provides enhanced clinical and service support for caregivers of eligible veterans who require personal care services and meet other eligibility criteria. Services for caregivers include a monthly stipend, access to health insurance, mental health counseling, and respite care. Eligibility for PCAFC was recently broadened to include eligible veterans who served during any service era.[46] The Elizabeth Dole Home Care Act, passed by Congress and signed into law by President Biden in early 2025, will further expand and enhance veterans and their families' access to caregiving benefits.[47]

The VA also operates a self-directed HCBS option called Veteran-Directed Care (VDC), formerly referred to as VD-HCBS. The program is for veterans who wish to remain in their homes and communities and require personal care and assistance with ADLs. The program also supports veterans whose caregivers are experiencing significant burden. Veterans are given a flexible budget to spend in line with other similar cash and counseling models.[48] The program has been found effective in keeping veterans in their homes and decreased caregiver burden.[49]

STATE-FUNDED PROGRAMS

Fully state-funded programs allow states considerable flexibility to tailor programs to the needs of their citizens but are subject to budgetary constraints. Additionally, 44 states have passed versions of the Caregiver Advise, Record, and Enable (CARE) Act, which requires hospitals to record the name of the family caregiver on the medical record of care recipients; inform the caregiver when their loved one is to be discharged; and provide the caregiver with education and instruction of the medical tasks they must perform for the recipient at home.[50]

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